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Hepatitis C: a review of Australia's response

Prepared by

David Lowe and Ruth Cotton

for

the Department of Health and Aged Care

January 1999

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ISBN 0 642 39389 3

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Publication approval number: 2521

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Publications Production Unit (Public Affairs, Parliamentary and Access Branch)
Commonwealth Department of Health and Aged Care
Canberra

Acknowledgments

The Commonwealth Department of Health and Aged Care commissioned Mr David Lowe and Ms Ruth Cotton to conduct a review of Australia's response to hepatitis C. Mr Lowe and Ms Cotton were responsible for preparing the final report, for organising interviews, for integrating the information provided by other contributors, for analysing all the assembled information, and for developing the recommendations. They acknowledge and thank the following people for their contributions.

The review's Advisory Committee provided advice on all aspects of the review and commented on the draft report. The Committee consisted of Dr Andrew Penman, Professor Bob Batey, Dr Jim Butler, Mr Brendan Gibson, Ms Michelle Kosky, Dr Lewis Marshall, Mr Eamonn Murphy, Dr Aileen Plant, Mr Jeff Ward, Mr Jack Wallace, Mr Steven Hall and Mr Alex Wightman.

A number of people prepared various chapters of the report: Mr Matthew Law (Chapter 3), Ms Patty Correll (Chapter 4), Mr Justin Rowe (Chapter 5), Ms Frances Byers (Chapters 6 and 8), Mr Alan Shiell (Chapter 7), and Ms Catharina van Moort (Chapter 9). Mr Scott Bowden and Professor Stephen Locarnini prepared Appendix C, Ms Margaret Macdonald assembled the data for Figures 6.1 to 6.4, and Mr Alex Wightman and Mr Jeff Ward contributed to Chapter 8.

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Ms Chris Pirie edited the report.

Mr Chris Puplick, Chairperson of the Australian National Council on AIDS and Related Diseases, provided assistance and advice throughout the review.

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Summary and recommendations

Summary

The National Hepatitis C Action Plan has served Australia well: it placed hepatitis C on the public health agenda relatively early in the epidemic and encouraged the development of a consistent national approach.

Australia's response to hepatitis C has been further enhanced by the disease's incorporation in the National HIV/AIDS Strategy 1996–97 to 1998–99 as a related disease. This has provided a place at the national advisory table for the advocates of hepatitis C, additional Commonwealth funding, and increased prominence for what is a serious public health concern.

At the State and Territory level the increased awareness of the problems posed by the hepatitis C epidemic has contributed to an increase in the supply of needles and syringes and some enhancement of other education and prevention and care and treatment programs.

In the past two years it has, however, become obvious that a more assertive response to the epidemic is necessary. Several factors have prompted this realisation:

- a growing understanding of the significance of hepatitis C's impact in Australia;
- more effective advocacy from community-based organisations and professional groups;
- leadership provided by the Australian National Council on AIDS and Related Diseases in giving hepatitis C greater prominence in national policy making;
- increased commitment, on the part of governments and public health officials, to tackling the problem.

But, despite these developments, Australia's response is still seriously lacking in a number of respects:

- a lack of impetus, momentum and sense of urgency;
- the high number of new infections, which is evidence that existing public health interventions have not done enough to bring the disease under control;
- the absence of an up-to-date, strategic document that outlines how Australia will continue to respond to hepatitis C and, in particular, the challenges identified by this review. Although the Action Plan and the accompanying Nationally Coordinated Hepatitis C Education and Prevention Approach were very useful for mobilising the initial response to the epidemic, they no longer have the currency that is necessary for a continuing response to this pressing problem.

The challenges hepatitis C presents—as outlined in this review—pose particular difficulties for governments, public health officials, community-based organisations and health professionals. The difficulties stem from the large number of people already infected; the high annual incidence rate; the difficulty associated with interventions where the main risk factor is connected with an activity that is both illicit and highly stigmatised; a shortage of research findings to guide the design of a response; and the limited range of treatments currently available. If Australia is to respond effectively to the epidemic, each of the challenges must be confronted and overcome.

Although the challenges the reviewers have identified need to be tackled in an integrated fashion, the very high number of new infections occurring each year means that priority must be given to reducing the number of new hepatitis C infections. It will also be necessary to concentrate on research into the efficacy of education and prevention initiatives. At this stage, policy and program planners are largely reliant on program logic in determining which approach to take. What is needed is research that will uncover best-practice models that maximise marginal gains. Nonetheless, the need for an enhanced national response is urgent: action is necessary before research findings become available.

This review has also identified the essential components of the future national response to hepatitis C. Chapter 12 provides detailed discussion of directions and priorities to guide Australia's response in the light of the five challenges. Following are the essential components of an organised national response to those challenges. The Commonwealth should consider developing performance indicators based on the essential components and could use the indicators in developing the next round of Public Health Outcome Funding Agreements with the States and Territories.

Challenge 1—reducing the number of new hepatitis C infections

1. Provision of sterile needles and syringes, sufficient to meet demand, so as to reduce the prevalence of unsafe injecting.
2. Education programs aimed at reducing illicit drug use, particularly injecting drug use.
3. Provision of drug treatment programs such as methadone maintenance, sufficient to meet demand, so as to reduce the prevalence of unsafe injecting and the prevalence of illicit drug use.
4. Provision of safe injecting places to reduce the prevalence of unsafe injecting.
5. Education programs targeting injecting drug users through specialist agencies (such as peer-based programs developed and undertaken by user groups) and the use of mainstream health care workers, so as to reduce the prevalence of unsafe injecting and the prevalence of injecting.
6. Education programs and the provision of preventive measures in prisons.

7. Measures to reduce the number of injecting drug users in correctional centres through the adoption of cautioning systems for first offences and diversionary sentencing.
8. Removal of legal impediments to achieving a higher proportion of safer injecting amongst injecting drug users.
9. Establishment of an agreed core service structure and realistic output targets for education and prevention services.

Challenge 2—improving treatment and care for people with hepatitis C

1. Development of an agreed policy on hepatitis C testing.
2. Development and implementation of primary health care models, by general practitioners and public sector community clinics to deal with the health care needs of population groups with hepatitis C to ensure optimal access to counselling, testing and management
3. Enhancement of the capacity of liver clinics in hospital settings, sufficient to meet demand.
4. Access to the full range of treatment and care services for people who are incarcerated.
5. Established mechanisms for the continuing education of general practitioners and others who work in hepatitis C treatment and care and the incorporation of advances in care in clinical practice.
6. Provision of information and support, including health maintenance and monitoring for people with hepatitis C, through community organisations such as hepatitis C councils and user groups.

Challenge 3—'getting the research right'

1. Adherence to a set of guiding principles.
2. Transparent processes for determining research priorities and for funding the 'best buys' for Australian hepatitis C research.
3. A research plan that sets out priorities, mechanisms for funding, and the role of national research centres funded under the National HIV/AIDS Strategy and the National Drug Strategy.
4. Established processes for the commissioning of research to guide specific aspects of the national response to hepatitis C.
5. Recognition of the important role of social research in improving the design and delivery of interventions.

6. Adequate surveillance mechanisms.
7. Mechanisms or processes to encourage dialogue between social researchers and people involved in the design and delivery of education and prevention initiatives, to allow for the identification and refinement of research questions, the dissemination of findings, and translation of the findings into practice.

Challenge 4—extending partnerships

1. A partnership approach at all levels, with priority given to extending and supporting affected communities' participation.
2. Establishment of structures and processes—at national and State and Territory levels—that facilitate stakeholders' contribution to policy and strategy development and decision making (see also challenge 5).
3. User groups and hepatitis C councils, appropriately resourced on a recurrent basis, in each State and Territory.
4. Each State and Territory hepatitis C strategy having a component that accommodates the need to build intersectoral partnerships.
5. Demonstrated effort—at national and State and Territory levels—towards building an integrated approach to the public health challenge presented by hepatitis C, involving the National Drug Strategy and law reform. A bipartisan political approach is necessary to support these efforts.

Challenge 5—clarifying structures, roles and responsibilities

1. Advisory and coordinating mechanisms—at national and State and Territory levels—with capacity for a dedicated focus on hepatitis C.
2. A new strategic document on hepatitis C that provides a framework for the development of more detailed action plans by all jurisdictions, including the Commonwealth.
3. National mechanisms for monitoring progress and supporting the partnership to overcome obstacles to attaining identified goals and, in each jurisdiction, mechanisms for monitoring implementation and progress towards goals. These mechanisms would be existing structures.
4. User groups and hepatitis C councils, appropriately resourced on a recurrent basis, in each State and Territory (see also challenge 4).
5. Adequate funding to support activities that flow from the strategic approach.
6. Inclusion of hepatitis C outcomes in Public Health Outcome Funding Agreements between the Commonwealth and the States and Territories.

7. The National Public Health Partnership to extend its leadership role in promoting integration across national strategies by establishing an Integration Working Party consisting of representatives of both the hepatitis C and National Drug Strategy policy areas. The Working Party should identify areas for increased collaboration and consistency, so that efforts in the two areas enhance and support one another. This commitment to integration should be reflected through formal mechanisms at the State and Territory level.

Directions and priorities

The central recommendation of this review is that Australia develop a national strategy for taking action in relation to hepatitis C. This should be done as a matter of urgency, and the strategy document should have three main functions:

- to define the directions and priorities for taking up the challenges identified by this review;
- to form the basis for implementation of the essential components of an organised national response to hepatitis C, as identified by this review;
- to clarify the structures that will be used to implement the Strategy and the respective roles and responsibilities of all elements of the partnership.

Chapters 10 to 13 outline recommended directions and priorities. These should be used as the basis for development of the strategy for redressing the problem of hepatitis C.

The analysis of the different models for configuring Australia's response to hepatitis C—separate hepatitis C and HIV/AIDS strategies; further development of the 'HIV/AIDS and related diseases' approach; or a communicable diseases framework that takes in specific sub-strategies—suggests there is much to be gained from integrating the approach to hepatitis C with the approach to other communicable diseases where there is substantial cross-over and where efficiencies can be achieved and synergies exploited.

One risk of such integration is, however, that strategies can become overgeneralised. It is essential that any strategy dealing with hepatitis C clearly define how the challenges specific to that disease will be met. This clear definition is lacking at present, and without it significant progress will probably not be made. Placing hepatitis C within a communicable diseases framework must be done in such a way as to allow for the description of strategic approaches specific to hepatitis C (and other diseases) within an overall, integrated framework.

Historically, the response to hepatitis C has been developed within a disease framework. It is, however, well recognised that the main route of transmission of the virus is unsafe injecting by drug users. It is therefore reasonable to expect that the way Australia responds to illicit drug use will have a powerful influence on the future course of the hepatitis C epidemic. It is essential that the prevention of transmission hepatitis C be seen as part of the 'core business' of the National Drug Strategy.

Any strategic initiatives and arrangements emerging from this review must be very closely monitored in terms of their effect in meeting the five challenges, especially that of reducing the number of new hepatitis C infections, and in relation to the social and economic effects of hepatitis C. This is particularly important in the absence of dedicated funding.

Recommendations

1. The reviewers recommend that, in close consultation with the States and Territories, community-based organisations, health professionals and other interested parties, the Commonwealth Department of Health and Aged Care develop a National Hepatitis C Strategy. The Strategy document should clarify four central elements:
 - the directions and priorities for taking up the challenges identified by this review;
 - the essential components of an organised national response to hepatitis C, as identified by this review;
 - the structures that will be used to implement the Strategy and the respective roles and responsibilities of all elements of the partnership;
 - mechanisms, developed cooperatively by funding bodies, for monitoring and evaluating progress with implementation, the data obtained being used for program improvement and accountability purposes.
2. The reviewers recommend that the National Hepatitis C Strategy be developed and placed within the framework of a strategic response to other communicable diseases, so as to maximise efficiencies and exploit synergies. The Strategy should, however, recognise that in some areas disease-specific approaches are needed to respond to particular challenges. Thus the overall framework must allow for the development of pathways that are tailored to particular diseases.
3. Considering that patterns of injecting drug use will have a powerful influence on the future course of the hepatitis C epidemic in Australia, the reviewers recommend that prevention of transmission hepatitis C be seen as part of the 'core business' of the National Drug Strategy.
4. The reviewers recommend that those responsible for implementation of national communicable diseases strategies and the National Drug Strategy, as well as the National Public Health Partnership, give consideration to the development of mechanisms that will lead to a high degree of integration between the national responses to hepatitis C and illicit drugs. This should include consideration of the establishment of an Integration Working Party.

Part One

Overview

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1 Context, challenges and models

1.1 The review

This is the first review of Australia's response to the hepatitis C epidemic. The Commonwealth Department of Health and Aged Care commissioned the review, and the Public Health Planning Branch of the Department's Population Health Division was given carriage of it. Staff of the Branch collaborated with Mr David Lowe and Ms Ruth Cotton (the reviewers) and other experts to produce this report—Chapter 2 lists those who contributed. The review's terms of reference, which are also set out in Chapter 2, required the following:

- documentation of the extent of the problem—in terms of the prevalence and incidence of infection, the economic costs to Australia, and the social impact of the disease;
- an assessment of the performance of the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach;
- a broader analysis of the current national and State- and Territory-level responses to the epidemic;
- recommendations on directions and priorities for national action.

1.1.1 Consultation

Extensive consultation was central to the review.

- The Advisory Committee, consisting of people with a diverse range of expertise, met regularly to discuss the review methodology and results.
- A public advertisement calling for submissions appeared in the national press and a wide range of interested individuals and groups were invited to present submissions.
- The consultants engaged to conduct the review held interviews in each State and Territory and with Commonwealth officials.
- The Department of Health and Aged Care conducted surveys of all jurisdictions and many community-based organisations to obtain information about implementation of the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach.
- A national meeting of interested parties was held to consider findings in the areas of epidemiology, economic analysis, implementation of the Action Plan and the Education and Prevention Approach, the challenges, proposed directions, and models for a response to the hepatitis C epidemic.

1.2 The nature of the problem

The hepatitis C virus was identified in 1989 and a diagnostic test for it became available early in 1990. It is now known that the virus has been present in Australia for at least 20 years.

1.2.1 Epidemiology

It is believed that 80 per cent of people who are exposed to hepatitis C become chronically infected and are able to transmit it. For the majority of people chronic infection is asymptomatic. Cirrhosis may develop in up to 20 per cent of people with chronic infection, generally at least 20 years after the time of infection. If cirrhosis does develop, it may run an indolent course. Some people will, however, suffer liver failure and some of them will ultimately develop liver cancer.

Over 110 000 hepatitis C diagnoses have been reported for Australia between 1991 and 1997. Transmission is mainly caused by blood-to-blood contact and studies suggest that 75 to 80 per cent of infections have been a result of injecting drug use—indeed, hepatitis C is epidemic among injecting drug users. The high prevalence among this group means that even infrequent risk-taking behaviour allowing transmission of blood-borne viruses is sufficient to maintain a high rate of transmission. In addition, the high concentration of infectious particles in the blood means that only a small amount of blood is needed to infect someone.

In 1998 a Hepatitis C Projections Working Group was convened under the auspices of the Australian National Council on AIDS and Related Diseases Hepatitis C Subcommittee to develop estimates of the prevalence, incidence and impact of hepatitis C in Australia. Because of methodological difficulties associated with hepatitis C epidemiology, however, direct estimation of prevalence in Australia is uncertain and direct estimates of incidence are not available. To complement direct estimates of prevalence, the Working Group developed models of the hepatitis C epidemic in Australia; the following are the Group's best estimates based on the models.

- The cumulative number of people infected with hepatitis C by the end of 1997 was 197 000.
- Hepatitis C incidence in 1997 was 11 000.
- Eighty per cent of cumulative hepatitis C infections were a result of injecting drugs, 7 per cent were a result of receiving blood, and 13 per cent were a result of other factors.
- Ninety-one per cent of hepatitis C infections acquired in 1997 were a result of injecting drugs and 9 per cent were a result of other factors.
- The number of people living with cirrhosis caused by hepatitis C infection in 1997 was 8500.
- There were 80 cases of hepatitis C-induced liver cancer in 1997. This number is expected to at least double by 2010.

The modelled estimates are consistent with direct estimates, indicating the robustness of the modelled estimates.

Using the modelled estimates, it is possible to make the following estimates of disease progression. For every 11 000 infected individuals it is estimated that

- 2750 will clear the virus;
- 8250 will develop chronic long-term hepatitis C;
- 880 will develop cirrhosis 20 years after hepatitis C infection;
- 220 will experience liver failure 20 years after hepatitis C infection;
- 88 will develop liver cancer 20 years after hepatitis C infection.

The global picture

Surveillance of hepatitis C prevalence and incidence in global populations presents difficulties. Hepatitis C infections are largely under-reported in routine notification systems and multi-faceted approaches are needed to detect cases and determine the extent of the disease at a population level.

Nevertheless, global hepatitis C surveillance data and published studies in specific populations have established that large numbers of people are chronically infected and that infection continues to be transmitted. In the United States hepatitis C is believed to be the most common blood-borne infection, with prevalence estimated at 1.8 per cent of the population—about 3.9 million people. In the European Community, the estimated prevalence is about 0.9 per cent; in the United Kingdom it is about 0.3 to 1.0 per cent. Australia's estimated prevalence is 1.1 per cent. Although data for developing countries are limited, the estimated prevalence for a number of South East Asian countries (including Malaysia, Indonesia and China) ranges from 1.0 to 2.5 per cent; a study of Western Province in Papua New Guinea revealed an estimated prevalence of 4.1 per cent.

With the introduction of screening for donated blood in industrialised countries, the prime risk factor for hepatitis C infection in those countries is injecting drug use. Studies of injecting drug users consistently demonstrate high rates of hepatitis C infection and a high incidence of new infections.

1.2.2 The personal and social impacts of a hepatitis C diagnosis

The initial diagnosis of hepatitis C can be a frightening and alienating experience. The person may not have been told they were being tested for the virus and may not have received post-test counselling. The diagnosis will give rise to many questions, from basic facts about the disease to its impact—now and in the long term—on the affected person and their family, friends and work colleagues. Perhaps a past history of injecting drug use may bring to the fore experiences the person thought were well in the past.

The health professional's skill at this early stage is vital in influencing the nature of the infected person's future contact with the health system, as well as their adaptation to living with a chronic condition.

The newly diagnosed person also has to make decisions about who to tell about the diagnosis and to be aware of the possible consequences. Many report feeling isolated, 'permanently scarred' or 'tainted'. People living with hepatitis C live with fears, myths and misinformation about the disease and with the projected anxieties of others. Reminded that they have the disease many times in their day-to-day lives—when confronted with the possibility that they might infect someone—they can never forget.

Discrimination, or the potential for it, is often reported. Hepatitis C has acquired the label 'the drug addict's disease', thus adding to the stigma attached to a communicable disease. Discrimination can occur in social networks and in institutional settings such as schools, hospitals, health and dental clinics, and child-care facilities, affecting access to services. In a study of 37 people with hepatitis C, Crofts and Louie (1997) found a high proportion of people suffered from discrimination and that instances of discrimination had substantial personal implications for 83 per cent of their subjects. Much discrimination experienced by people with hepatitis C echoes people's attitudes towards injecting drug users.

Knowledge and behaviours relating to transmission of hepatitis C

Chapter 6 discusses a range of research work, the results of which provide some insight into the effect of education and prevention initiatives thus far. In relation to knowledge of hepatitis C, the results of two large surveys—one of 3550 government-school students in years 10 and 12 (Lindsay et al. 1997) and the other of 3039 men who have sex with men (Crawford et al. 1998)—suggest limited or patchy knowledge. The students' poor knowledge of hepatitis C contrasted dramatically with their consistently high level of knowledge about the transmission of HIV.

An analysis of research into the changing patterns of risk behaviour among injecting drug users reveals a complex picture, especially in relation to needle sharing. Although the general pattern of a decline in sharing is confirmed, the data for 1995 onwards suggest that in the early 1990s sharing rates did not decline as rapidly as suggested by some studies. Further investigation is needed to understand whether other aspects of injecting behaviour have changed during the 1990s. The number of available needles and syringes expanded very substantially, but the findings add weight to the argument for the provision of accompanying health-promotion programs, which is essential if behavioural change among injecting drug users is to be maintained and extended.

1.2.3 The cost of hepatitis C

Good decisions about priorities for public health initiatives are based on good data about the nature and extent of the problem at issue and on estimates of the present and future cost to the community, affected individuals and their families and friends. The economic analysis presented in this report provides a basis for discussion of the potential cost-effectiveness of hepatitis C-related education, prevention and treatment initiatives. Estimates are provided by Shiell (1998) and based on epidemiological data provided to the review.

'Direct costs' refers to costs incurred directly as a result of action to tackle the disease; this includes expenditure on research, surveillance, prevention, diagnosis and

treatment. Prevalence-based costs and incidence-based costs are the two types of direct costs estimated for this analysis.

The prevalence-based costs of hepatitis C infection are the costs incurred in a given year by people already infected. In 1996–97 these costs amounted to at least \$75 million, although this is thought to be an underestimate.

The incidence-based costs of hepatitis C are the lifetime costs incurred by a cohort of people each infected with hepatitis C at the same time. Although these costs are more difficult to estimate than prevalence costs—they require projections of disease transition in a cohort of newly infected people—they are potentially more useful because they describe the savings that could be realised from an effective prevention program.

The undiscounted cost of treating hepatitis C in a cohort of 1000 newly infected people amounts to nearly \$13 million over 50 years; the discounted cost (discounted at 5 per cent) is \$6 million. Again, this is probably an underestimation of the future costs associated with hepatitis C. The figures presented in this analysis are remarkably similar to those in the only other study of incidence-based costs (Brown & Crofts 1998), despite differences in method.

The study assumes that 30 per cent of people with chronic hepatitis C infection, 80 per cent of people with cirrhosis and all people with more severe long-term sequelae seek medical attention. Thus, the reason the incidence costs are fairly low is that many people with hepatitis C do not impose major costs on the health system. But the subset of affected people who suffer severe sequelae (cirrhosis or liver cancer or requiring liver transplantation) can impose enormous costs. The costs are disproportionately concentrated on people with severe sequelae, so the greatest cost benefit of enhanced education and prevention should be seen as having an impact at the severe end of the disease spectrum.

The use of interferon has become much more cost-effective because the drug's price has dropped and there have been improvements in clinical practice. One improvement in clinical practice concerns more targeted administration of the drug to people with hepatitis C who are most likely to benefit from treatment. A conservative approach to broader application of interferon, and interferon in combination with ribavirin and PCR (polymerase chain reaction) testing, may be warranted because the longer term cost-effectiveness of these approaches is as yet untested. Genotyping could, in the future, be used to determine who best benefits from treatment with interferon and ribavirin.

Because of its documented high cost-effectiveness in preventing HIV/AIDS, the needle and syringe exchange program functions as a 'free good' for hepatitis C. There is evidence that a reduction in hepatitis C incidence among injecting drug users, coincident with the introduction of needle and syringe exchanges in Australia, has meant 2000 fewer people exposed to the virus each year. This implies cost savings with a discounted present value of \$12 million a year. The expansion of needle and syringe exchanges in the past couple of years is therefore easily justified, and governments should be confident that investing additional resources in this area will produce good returns.

The majority of other hepatitis C prevention and treatment interventions are reasonably untested and fall into the category of high-risk but possibly high-benefit interventions. The incident costs of hepatitis C provide an indication of the minimum benefits that could be realised from an effective prevention campaign, but uncertainty about what works best and by how much limits the usefulness of this approach.

Alternatively, the 'burden of illness' approach to priority setting encourages one to think about the relative size of the problem (the burden of illness) rather than what can be gained by reallocating existing resources or investing new resources. Giving priority to areas where there are demonstrably high health gains to be made relative to the additional investment required may be too conservative. Hawe and Shiell (1995) have suggested taking a 'portfolio approach' to public health investment, whereby a portfolio contains a judicious mix of blue-chip investments (which offer secure health gains at reasonable cost) and high-risk investments (unevaluated interventions that may or may not produce health gains). Current treatment options fall into the high-risk category. Because of their enormous cost and high risk, it could be argued, in economic terms, that more education and prevention spending to increase the effectiveness of the needle and syringe exchange program (and even of untested interventions that might have a synergistic effect in increasing the program's effectiveness) would be a much better investment than more high-risk investment in treatments.

The indirect costs of hepatitis C relate to loss of production—through, for example, days lost because of treatment and premature mortality, changes in employment participation, and lost productivity. The indirect cost of hepatitis C-related disease in 1996–97 amounted to \$32.5 million. Indirect costs associated with a cohort of 1000 newly infected people would amount to \$33.6 million over 50 years, or \$17.5 million using a 5 per cent discount rate. These estimates are considered to understate the loss of production.

A subgroup of the review's Advisory Committee made some suggestions for improving the economic analysis of the cost of hepatitis C and identified areas for further research that could enhance the validity of cost-effectiveness studies. These suggestions are summarised in Attachment I to Chapter 7.

1.3 Australia's response to date

By international standards, Australia responded quickly to the hepatitis C epidemic by enhancing its hepatitis C-related education and prevention, treatment and care, and surveillance infrastructure.

1.3.1 National policy development

A number of initiatives were central to the national response:

- securing the blood supply in 1990, following the availability of a diagnostic test for hepatitis C—since this time the risk of acquiring hepatitis C through blood transfusions has been considered minimal. A blood transfusion 'Look Back' policy

for hepatitis C was introduced in 1994, to trace and refer for counselling and follow-up people who may have received contaminated blood;

- providing access to testing for hepatitis C from 1990, funded through the Medicare Benefits Schedule;
- identifying the need for national public health action in response to hepatitis C by late 1993—calls for information, advice and a national response had begun in the early 1990s, from affected individuals who formed hepatitis C councils, injecting drug user groups, needle and syringe exchanges, and health care workers. Gastroenterologists also had an important role in bringing the epidemic to note and developing a response. Within a few years of the test becoming available, it was apparent that a large number of Australians had been exposed to the virus;
- developing a National Hepatitis C Action Plan in October 1994 and a Nationally Coordinated Approach to Education and Prevention in November 1995—the Plan makes recommendations for action in four priority areas: surveillance and epidemiology; testing; clinical management and counselling; and education and prevention. In developing the Action Plan, the Commonwealth consulted widely. It was agreed that each jurisdiction would fund its area of responsibility for implementation;
- incorporating hepatitis C in the infrastructure of the National HIV/AIDS Strategy in the areas of education and prevention and research, where there are clear and direct links, while identifying specific gaps in the public health response. The Australian National Council on AIDS and Related Diseases was re-formed in December 1996 and the Intergovernmental Committee on HIV/AIDS and Related Diseases was re-formed in June 1997. ANCARD and IGCARD ensure that where policies and programs for HIV/AIDS and hepatitis C overlap—in areas such as education, prevention and research—a joint approach will be developed;
- providing access to treatment with interferon (available as a section 100 pharmaceutical benefit since 1994) through specialist treatment centres and developing treatment and management guidelines for health practitioners.

Because Australia's National Hepatitis C Action Plan comes within the context of the National HIV/AIDS and National Drug Strategies, responses to hepatitis C have been shaped by policies, infrastructure and processes underpinning these two Strategies. Among the influences have been the partnership approach, the concept of harm minimisation, and the development of programs and policy based on research and surveillance.

1.3.2 Implementation of the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach

The review was able to develop a systematic assessment of implementation from the responses to a survey sent to State and Territory health departments and the Commonwealth Department of Health and Aged Care. The results provide a useful overview of Australia's response to hepatitis C from October 1994 until March 1998,

although the quality of the responses varied because in some cases limited resources were available at the time. In addition, most hepatitis C-related initiatives have not been evaluated, so the effectiveness measures are subjective, being solely from the perspective of the reporting jurisdiction.

The National Hepatitis C Action Plan

Survey respondents considered that most of the recommendations in the National Hepatitis C Action Plan have been implemented with moderate effectiveness, leading to the development of improved strategies and the need for continuing work. Most State and Territory governments also considered that the Action Plan had provided a good background on hepatitis C and a formal mandate and framework for action. Deficiencies and the need for further work were, however, noted.

Epidemiology and surveillance

Respondents claimed that the Action Plan's recommendations for improving the surveillance and epidemiological information base for hepatitis C have largely been implemented but with modest results owing to a number of persistent methodological problems.

In relation to epidemiology and surveillance the Action Plan recommended the adoption of a standard definition of incident and prevalent cases of hepatitis C; a 12-month pilot study involving follow-up of seropositive tests to enable the optimal identification of incident cases and the collection of information on risk factors for incident and prevalent cases; development of a system for following up reports of cases of hepatitis C; collection of surveillance data; and the development of a uniform minimum data set at the national level.

The report of the pilot study concluded that, because of its labour-intensive methodology, routine surveillance may not be the best way of gathering detailed epidemiological data on hepatitis C. Other approaches, such as sentinel screening programs and studies in selected cohorts, were recommended. As a result, the National Centre in HIV Epidemiology and Clinical Research is being contracted to develop a national strategy for hepatitis C surveillance and a Communicable Diseases Network of Australia and New Zealand hepatitis C surveillance reference group has been established.

Hepatitis C testing strategy

The Action Plan's hepatitis C testing recommendations have been fully implemented according to the Commonwealth Department of Health and Aged Care, which was responsible for their implementation. The recommendations related to evaluation of hepatitis C test kits, access to first-line tests, and protocols for conducting tests.

Management, counselling and treatment of patients

Respondents claimed that the recommendations relating to management, counselling and treatment of patients have been either fully or partially implemented, with moderate effectiveness. The recommendations covered provision of counselling and referral services; post-test counselling; development of diagnostic and clinical guidelines for the management of antibody-positive or antibody-indeterminate patients

and the management of interferon; development opportunities for medical and other health professionals, linked to diagnostic and clinical guidelines; and assistance to relevant community-based groups to help them meet the support needs of people with hepatitis C.

A number of continuing problems were identified: provision of adequate pre-treatment information; the impossibility of ensuring that all GPs are adequately trained to counsel patients effectively; service providers' negative attitude towards people with hepatitis C who continue to inject drugs; the lack of continuing funding; inadequate provision of counselling services; and poor access for migrants, Indigenous Australians, prisoners and their families, and clients of mental health services.

Education and prevention

Most of the Action Plan's recommendations relating to education and prevention were fully or partially implemented but their effectiveness is unmeasured, according to respondents. The Nationally Coordinated Hepatitis C Education and Prevention Approach is discussed in the next section.

The recommendations in the Action Plan related to development of a national education and prevention approach; review of hepatitis C educational material; review of occupational health and safety guidelines on exposure to blood and body fluids; and greater availability of sterile injecting equipment.

Among the efforts to develop a nationally coordinated education and prevention approach are the Approach itself, the establishment of national committees such as the ANCARD Hepatitis C Sub-committee, the ANCARD Education Sub-committee, the IGCARD Education Managers Forum and the IGCARD Hepatitis C Education and Prevention Working Party, and the development of some national resource material.

State and Territory responses to the survey identified the following problems in relation to education and prevention: lack of funds; no resolution of the problem of an appropriate approach to a national media strategy (a national approach can be difficult because the States and Territories are at different stages of implementing various strategies); the fact that some state school systems oppose education about injecting drug use; the absence of formal reviews of education approaches; and deficiencies in gaining the attention of young people and developing material suitable for them.

The number of needles and syringes available continues to increase rapidly but there are gaps in geographical and temporal availability. Some jurisdictions have coped with large supply increases without increased funding, which affects their ability to provide free services with an educational component.

The Nationally Coordinated Hepatitis C Education and Prevention Approach

In the main, State and Territory governments have implemented many of the recommendations in the Nationally Coordinated Hepatitis C Education and Prevention Approach, although this varies according to what could be done without additional resources and, in many States and one Territory, according to priorities developed through consultations with interested parties. The Approach was deemed useful, but most States had developed their own strategies.

Broadly, the Approach's recommendations covered injecting drug users; tattooists and skin penetration; the general community; decision and policy makers; custodial institutions; health service providers generally; treatment, care and support education for health service providers; educating health service providers about prevention of occupational exposure risks; and support for people affected by hepatitis C.

The following are among the Approach's achievements and shortcomings thus far.

- The number of needles and syringes distributed nationally increased from 13.9 million in 1994–95 to 15.5 million in 1995–96 and 19 million in 1996–97.
- The number of people in Australia undergoing methadone therapy doubled between 1993 and 1997.
- The national survey of injecting drug users attending needle and syringe exchanges suggests that in 1997 fewer users were engaging in behaviours that place them at risk of transmission of HIV, hepatitis B and hepatitis C.
- Work relating to tattooists and skin penetration, including revision of legislative standards, is continuing.
- Very little has occurred in relation to educating the general community about hepatitis C.
- Recommendations relating to decision and policy makers have largely been implemented.
- Most, but not all, States and Territories have introduced some decontamination measures, preventive initiatives, and education services in some custodial institutions. The effects are largely unknown. Continuing gaps and problems are of great importance given the high incidence of hepatitis C in prisons.
- There remains a need for injecting drug users to have access to well-educated GPs who understand their condition. Most States and Territories have offered a degree of training, but much more needs to be done, so that anyone with hepatitis C who requires primary care can get it, along with relevant information. The Royal Australian College of General Practitioners Hepatitis C Education Project will provide a framework for GP education if an implementation phase is resourced.
- Referral networks of suitably qualified counsellors have not been formally introduced in all States and Territories.
- Infection-control training and in-service development for health care workers tend to be ad hoc and variable, although this can be covered well by existing processes such as accreditation.
- Recommendations relating to support services for people with hepatitis C have been partially implemented in most States and Territories.

1.4 The review findings

1.4.1 The current response to hepatitis C: a summary

Incorporation of hepatitis C in the National HIV/AIDS Strategy 1996–97 to 1998–99 has raised the profile of the hepatitis C epidemic as a serious public health concern. ANCARD has assumed a national leadership role in relation to hepatitis C, and the partnership approach between government, the community and health care professionals is becoming more visible. The Commonwealth Government has recently allocated an additional \$1.7 million for research into and national programs connected with hepatitis C.

Some of the broad directions set out in the Action Plan retain a good deal of relevance, but in other respects the Plan has become dated, reflecting what was needed four years ago rather than now. The National HIV/AIDS Strategy does not define what strategies should be adopted to meet the challenges now posed by the hepatitis C epidemic. A clear, current, national agenda on hepatitis C has not been put forward to interested parties—national organisations, the States and Territories, corrections systems, regional health authorities, and professional organisations.

As noted, State-based strategies have been only partially implemented for a number of reasons, among them a shortage of funds resulting from intense competition for public health resources, limited political will, and a lack of community and media support. In addition, there has been only limited intersectoral action to resolve the problem of hepatitis C in areas such as corrections, juvenile justice and schools. Integration of hepatitis C concerns into the drug and alcohol sector has also been limited in most jurisdictions, although at the local level there have been many useful initiatives.

Added to this is the fact that, although there has been quite a lot of hepatitis C-related activity, there is a perception of a lack of impetus and that coordination of efforts could be more effective. Some activities appear to be piecemeal or ad hoc.

The stigma associated with hepatitis C as a result of its association with injecting drug use remains strong in the eyes of the community, policy makers and politicians. Stakeholders see this as contributing to the epidemic not being afforded sufficient priority as a national public health concern.

Discrimination against injecting drug users and people with hepatitis C is reported to be common. Apart from its adverse personal impacts, such discrimination creates a vicious cycle: it leads to non-disclosure, which exacerbates the disease's invisibility from the point of view of the general community, which intensifies marginalisation.

Public awareness of hepatitis C has not been successfully dealt with.

A basis for a renewed approach

Understanding of hepatitis C, particularly in relation to its epidemiology, the challenges associated with prevention, and the needs of those infected, has improved significantly

since the development of the Action Plan. This provides a good basis for revising and updating strategic directions.

Expanded knowledge of the virus's nature, and its similarities to, differences from and relationships with other types of hepatitis and HIV, provides the opportunity to refine our approach and to think about how any relationships might be reflected in services and programs. This is reinforced by the move away from disease-specific program barriers. At the program-funding and -planning level, the possibility of taking a broader approach arises. The National Public Health Partnership has the potential to provide an integrating mechanism to deal with problems such as hepatitis C that cut across different national strategic boundaries.

1.4.2 According hepatitis C sufficient priority

Although by international standards Australia has done relatively well in its response to hepatitis C, many people who were interviewed stressed that the virus is at present accorded insufficient priority in the areas of public health, treatment and care, and research. The commitment associated with a greater emphasis would result in more effective action to confront some of the considerable challenges posed by the virus.

Essential to the review process is an examination of how important hepatitis C is as a health concern and whether the current level of response in Australia is adequate.

The arguments both for and against doing more to respond are complex. Rather than seeing the question in polemical terms—do nothing or do everything humanly possible—the question can be recast to ask whether Australia's current efforts are sufficient to meet the challenges posed by the epidemic. There may be some merit in aspects of the argument that there is not a strong case for doing a great deal more to tackle hepatitis C, but on balance the reviewers find the contrary argument stronger. In assessing the case, it must be recognised that the epidemic is being fuelled by a large and continuing increase in the number of injecting drug users. The best available evidence suggests that this is likely to continue. Good monitoring and evaluation to measure the effectiveness of interventions continue to be essential.

Three main strategies may result in sufficient priority being accorded hepatitis C:

- presenting compelling data that spell out the prevalence and incidence of infection and the implications for health care and social well-being—this will reinforce arguments for an enhanced approach;
- education of the general community, mainly about the disease itself and discrimination—this needs to include education in settings such as schools and tertiary institutions and workplaces at possible risk;
- encourage a debate about hepatitis C that places it in the context of the current debate about drug law reform and treatment options—this would help to expand the drugs debate to take account of broad social questions rather than perpetuating the current fragmentation between law enforcement, community services, health, corrections, and so on.

1.5 Challenges for the future

Five basic challenges emerged from the analysis of the strengths and weaknesses of the current national- and State-level responses to hepatitis C and the opportunities and threats facing these responses:

- 1—reducing the number of new hepatitis C infections
- 2—improving treatment and care for people living with hepatitis C
- 3—‘getting the research right’
- 4—extending partnerships
- 5—clarifying structures, roles and responsibilities.

1.5.1 Challenge 1—reducing the number of new hepatitis C infections

Given the very large number of new infections in Australia each year (an estimated 11 000 in 1997), a strong case can be made that the most fundamental and pressing challenge posed by hepatitis C is achieving a reduction in the level of transmission. This high transmission rate suggests that current education and prevention initiatives are having insufficient impact. Hepatitis C infection was already well established among injecting drug users by the time needle and syringe exchanges and education programs for injecting drug users were introduced. Control of any infectious disease is far more difficult once a high level of prevalence among those at risk is entrenched.

The high prevalence of hepatitis C among injecting drug users (60 to 70 per cent), the virus's extremely infectious nature, and occasional needle sharing or other unsafe injecting practices mean that achieving a reduction in the level of transmission is a formidable task. The illicit nature of injecting drug use aggravates the situation. A combination of strategies may be needed, since no single approach is likely to deliver the desired results.

One needs to ask why the current education and prevention initiatives are having insufficient impact? There are a number of possible explanations.

- There are flaws in the design of interventions such as peer education.
- Injecting drug users most at risk of infection and people contemplating injecting drug use are not being effectively targeted.
- Perhaps the problem of effectiveness lies more with whether the amount of effort—especially in terms of output and reach for standard preventive measures such as the needle and syringe exchange program, methadone and user education—is commensurate with the size of the public health problem.
- The combination of the design of interventions, their targeting and the amount of effort may be unbalanced.
- Our understanding of the factors and behaviours leading to transmission of hepatitis C is incomplete.
- The alternative view, however, is that there are inherent difficulties in reducing the rate of hepatitis C infection and it is unrealistic to expect that we can do much

better than we are doing now—too great an expenditure would be required for limited gain.

Research evidence is needed to determine where the problem of limited effectiveness lies.

Prisoners constitute an especially important population group warranting further concerted preventive effort. Imprisonment is a risk factor for hepatitis C infection because of the lack or limited availability of the means of prevention in prisons and the over-representation of injecting drug users in the prison population. Tattooing with non-sterile injecting equipment is also thought to be a serious risk factor. The high turnover of prison inmates increases the opportunities for transmitting infection to the wider community. There are very good reasons for all jurisdictions to examine the adequacy of their current education and prevention programs in prisons and take remedial action where deficiencies exist.

Recommended directions and priorities

There is an urgent need to develop more effective education and prevention strategies. For the time being this will need to be done in the absence of research findings. An effective, multi-faceted approach might include the following strategies: reducing the prevalence of unsafe injecting; reducing the prevalence of injecting; enhancing education for injecting drug users; removing legal impediments to prevention; using treatment and care services in secondary prevention; improving infection control in the skin penetration industry; setting achievable targets for education and prevention; and developing an effective vaccine.

Reducing the prevalence of unsafe injecting

The prevalence of unsafe injecting may be reduced through the further expansion of the needle and syringe exchange program to meet distribution targets based on injecting drug users always using sterile injecting equipment. Such expansion could be achieved through deregulation of the approval process for distribution of needles and syringes, so that sterile injecting equipment is available from a much wider range of outlets, for instance, or through the use of alternative distribution mechanisms (such as vending machines) to maximise access, particularly out of hours.

Although surveys have revealed strong community support for the needle and syringe exchange program, there have been instances of resistance that have created political problems for the program in some jurisdictions. This may militate against the program's further expansion. There is also a need for more evidence of the reduction in new infections that could be achieved from any expansion of the program.

Reducing the prevalence of injecting

Reducing the prevalence of injecting will reduce the number of people at risk of infection. Initiatives in this area fall into four broad groups:

- reducing the uptake of illicit drugs, particularly drugs that are injected;
- attempting to shorten people's injecting 'careers';

- making available information on non-injecting routes of administration for illicit drugs, within a range of harm-minimisation options, and providing equipment to encourage avoidance of injecting;
- introducing diversionary sentencing practices to reduce both the number of injecting drug users and the prevalence of hepatitis C in prisons, thus reducing the risk of transmission in this setting.

Enhancing education for injecting drug users

Enhancing education programs for injecting drug users may result in an increase in safe injecting or curtail people's injecting careers, or both. Among the possible initiatives are improved targeting of groups of injecting drug users known or believed to be at greater risk of hepatitis C infection (for example, prisoners, certain ethnic groups, young and new users, and marginalised users such as the homeless); increased emphasis on the delivery of clear and consistent education and prevention messages to injecting drug users who are already infected; and enhancing the capacity of user organisations to provide peer education, support and advocacy for their constituents.

Removing legal impediments to prevention

Laws that act as an impediment to the prevention of blood-borne infections among injecting drug users should be reformed. If this is to occur, bipartisan support for harm minimisation is essential.

A clear process for consideration of necessary legal reforms should be identified. This could be done through the appropriate sub-committee of ANCARD, in tandem with legal matters being considered by the National Public Health Partnership.

Using treatment and care services in secondary prevention

Treatment and care services could play a secondary prevention role. The very fact of contact with the health care system may prompt injecting drug users to engage in safer behaviour. This can be reinforced if treatment and care services take the opportunity presented by contact to deliver education and prevention messages. Interventions to help clients resolve life problems may also have the effect of reducing the risk of infection by promoting a more stable lifestyle. As hepatitis C treatments improve and a higher percentage of infected people become free of the virus, the use of treatment as a secondary prevention strategy could become even more important. This should be kept under review.

Improving infection control

Initiatives to improve infection-control procedures in the tattooing and skin-penetration industry could be pursued.

Setting achievable targets for education and prevention

The basic service structure needed to reduce the transmission of hepatitis C should be agreed on nationally (through IGCARD) and described in a document detailing Australia's strategic approach to hepatitis C. It is also important to identify achievable targets for services that are proposed. IGCARD should oversee development work in this area, in close consultation with ANCARD, the Australian National Council on Drugs and the Intergovernmental Committee on Drugs.

Developing an effective vaccine

The development of an effective vaccine for hepatitis C poses considerable difficulties because of the complex nature of the virus. For the foreseeable future, therefore, strategies aimed at reducing transmission of the virus need to be based on education and prevention.

1.5.2 Challenge 2—improving treatment and care for people living with hepatitis C

Although all State and Territory authorities have devoted additional resources to care and support for people with hepatitis C, some barriers to success persist.

The number of hepatitis C tests performed has increased in the past five years, and there is evidence of a high and increasing proportion of users who report having been tested at some stage—in 1995, 77 per cent of injecting drug users surveyed reported having been tested; in 1996 the proportion was 80 per cent and in 1997 it was 84 per cent.

Nevertheless, if estimates of prevalence are accurate, many people with hepatitis C infection remain undiagnosed. Among the possible reasons for this are lack of awareness of risk (particularly for people who used to inject drugs but no longer do so); for marginalised at-risk people, alienation from the health system; the stigma associated with the disease; concerns about confidentiality and a positive result; and, importantly, the absence of symptoms. There is at present no national policy on testing, although it is common practice in all jurisdictions for injecting drug users in contact with the health system to be offered hepatitis C testing.

An infrastructure of treatment services has been established, and liver clinics operate in some major hospitals in each State and Territory. To date, the only approved treatment is interferon, which is available through liver clinics. Access to clinics can be limited by long waiting lists and the clinics' geographical distribution; this is especially problematic in rural and regional areas. Only a small proportion of people with hepatitis C infection are current or previous patients of liver clinics. This, however, is primarily due to the absence of clinical need rather than limited access.

Improving the capacity of a primary health care response by promoting GPs' greater involvement in hepatitis C medicine provides the opportunity to take a more holistic approach to the needs of people with the virus, particularly those with multiple health problems. Health monitoring and maintenance have been extensively promoted in HIV medicine, largely using a primary health care model. A similar approach could be adopted for hepatitis C. Links between liver clinics, GPs and community-based organisations need to be strengthened to facilitate this.

Other models that may improve injecting drug users' access to care, and access for people remote from current treatment centres, are youth agencies that have health clinics, sexual health centres, methadone clinics, outreach clinics at injecting drug user organisations, and specialist agencies such as the Kirketon Road Centre in Sydney's Kings Cross. The New South Wales demonstration projects may prove useful models.

Evidence now shows that significant improvements in treatment will occur with the introduction of combination treatment and efforts are underway to make this the standard treatment protocol. There is also some evidence that long acting interferon may improve treatment. Planning is needed to meet any increase in demand for treatment, particularly given the existing pressure on liver clinics.

Interferon has been trialled in combination with ribavirin and the benefits of the combination are now documented. Three publications reporting on treatment naïve and treatment relapse document this benefit for the two groups. Efforts are underway to make this the standard treatment protocol and the reviewers support these moves. A panel of experts convened by the American Food and Drug Administration has recommended that ribavirin be approved for the treatment of people with hepatitis C, but there are reports of serious side-effects associated with it, among them fatal heart attacks in older people.

Hepatitis C councils have been pivotal in providing emotional support and information for people with hepatitis C. This has included peer-based support groups, resource production, telephone information and support services, referral to other agencies, and interagency collaboration. Such support services need to remain a fundamental part of the councils' work.

Recommended directions and priorities

A number of strategies are central to improving treatment and care for people with hepatitis C: improving access to care; developing the capacity of primary medical and dental care; promotion of health maintenance and monitoring; promotion of good clinical practice; and improving data collection for health service planning.

Improving access to treatment and care

- Enhance the capacity of liver clinics in hospital settings, sufficient to meet demand.
- Provide hepatitis C treatments through non-hospital health facilities—for example, sexual health clinics, methadone clinics, medical services attached to youth agencies—to encourage greater treatment uptake by injecting drug users by reducing barriers to access.
- Improve access to counselling.
- Evaluate and publicise the New South Wales demonstration projects that aim to improve access.

Developing the capacity of primary medical and dental care

- Coordinate the implementation of GP education.
- Over time, further develop the shared-care model to allow trained GPs affiliated with designated treatment centres to prescribe hepatitis C treatments as a way of accommodating the possibility of a larger population in treatment.
- Include oral and dental health needs in a future national approach to hepatitis C, including consideration of accessibility.

Promotion of health maintenance and monitoring

- Take action to meet the demand from infected people for more information about treatment and lifestyle management, to encourage them to take control of their health. This should include information about complementary therapies.
- More emphasis on health monitoring and maintenance is needed—support the hepatitis C councils and user groups in this and develop an appropriate role delineation.
- Promote hepatitis A and hepatitis B vaccination for injecting drug users to reduce morbidity and mortality from dual infection.

Promotion of good clinical practice

- Develop processes for considering advances in clinical medicine and, where appropriate, promote their incorporation in clinical practice in Australia.
- Educate health care workers about reducing levels of stigma associated with and discrimination against injecting drug users with hepatitis C.

Improving data collection for health services planning

- There are two priority areas for improving estimates of the burden of hepatitis C–related incidence in Australia:
 - improved data on the development of mid-term sequelae of hepatitis C infection (such as fatigue, depression and the inability to work) and the social and economic impact of these conditions;
 - improved data on the proportions of diagnosed liver cancer and cirrhosis associated with or due to hepatitis C infection.
- This would be assisted by improving standardised data collection from treatment centres to enhance understanding of the outcomes of treatments and the natural history of hepatitis C infection.
- Projections relating to the quantity and type of future care and treatment, and the resource implications, are needed for use in State and regional health service planning.

1.5.3 Challenge 3—‘getting the research right’

Hepatitis C research is funded from a number sources: the National Health and Medical Research Council, CARG (the Commonwealth AIDS [and Related Diseases] Research Grants), commissioned research, and various national research centres with briefs in areas such as drugs, virology, epidemiology, and clinical and social research.

Although Australia's knowledge of hepatitis C has expanded greatly in recent years, the review has identified a number of important areas for which research data are needed to guide the nation's response to the epidemic. The following are elements of ‘getting the research right’:

- determining the right research priorities and considering what constitutes 'best buys' for Australian research;
- recognising the contribution of social research, especially in relation to refining education and prevention initiatives;
- striving for a balance between investigator-determined research and directed research, ensuring that strategic questions are being answered;
- fostering the research–practice interrelationship, allowing for a two-way dialogue on research priorities and design and for findings to be taken up in program design, refinement and implementation;
- multi-disciplinary collaboration wherever appropriate, to achieve a more complete understanding of effective interventions to lessen the impacts of hepatitis C;
- clarification of the role of the national centres funded from National HIV/AIDS Strategy and National Drug Strategy funds in relation to hepatitis C research;
- community involvement in setting priorities, planning and conducting research, and disseminating findings.

[Note that possible priorities in biomedical research are not outlined here: these are best determined by experts.]

Recommended directions and priorities

There are two important aspects to 'getting the research right': adherence to guiding principles and clearly determining research priorities.

Guiding principles

The research effort should be guided by the following principles:

- recognition of the contribution of social research, especially in meeting challenge 1;
- a balance between investigator-determined research and directed research;
- use and development of existing mechanisms to foster the research–practice interrelationship;
- encouragement of multi-disciplinary collaboration;
- community involvement in setting the research agenda, in the design and execution of research, and in the dissemination of findings.

Determining research priorities

The review has identified four basic areas for consideration when determining overall research priorities: surveillance; education and prevention initiatives; improving treatment and care; and clinical intervention.

Surveillance

Estimates of and projections for hepatitis C in Australia can be improved in three main ways:

- by improving methods of estimating the number of injecting drug users;
- by using national sero-surveys to develop unbiased population estimates of hepatitis C prevalence;
- by identifying groups of injecting drug users at particular risk of hepatitis C infection, to enable more refined targeting of education and prevention programs and to monitor the impact of these programs.

Education and prevention initiatives

Research into the following holds the potential to contribute much to the refinement of education and prevention initiatives:

- the reasons for injecting drug users continuing to share injecting equipment and barriers to safe practice;
- whether a further reduction in the sharing of needles and syringes and improvements in other aspects of safe injecting, through enhancing the sterility of the injecting process, would produce a significant decline in transmission of the virus;
- gaining a better understanding of the size of the injecting drug user population and its characteristics and dynamics;
- the reasons for choosing injecting over other routes of administration and (potential) incentives for and barriers to a transition from injecting to other routes;
- evaluating the effectiveness of different preventive strategies, including their cost-effectiveness, so as to provide a guide to what are the 'best buys' for limited budgets.

Improving care and treatment

Care and treatment can be improved in two main ways:

- by identifying the barriers to seeking testing for people who are or have been at risk of infection;
- by developing service models that will improve injecting drug users' access to primary and secondary treatment to meet the full range of their health care needs.

Clinical intervention

Clinical intervention can be improved in the following ways:

- through virological and immunological studies characterising the determinants of hepatitis C clearance during primary infection;
- through evaluation of the effectiveness of treatment as a prevention strategy;
- through investigation of the relationship between predictors of disease progression and responses to treatment;
- through evaluation of the efficacy and effectiveness of alternative therapies.

1.5.4 Challenge 4—extending partnerships

The partnerships philosophy was very successfully introduced as a public health strategy in Australia's management of the HIV/AIDS epidemic. Involving affected communities in finding solutions and responses appropriate to them continues to be fundamental to the partnership approach, chiefly because many of those affected are from marginalised groups, traditionally suspicious of mainstream health and legal systems.

In the case of hepatitis C, only limited attempts having been made to extend and refresh the partnership links needed to bring new vigour to Australia's response to the epidemic. Although Australia's experience of the value of the partnership approach to HIV/AIDS stands it in good stead for refining its response to hepatitis C, a number of important partnerships need to be developed or consolidated:

- the partnership between governments (Commonwealth and State and Territory) and people with hepatitis C (current and past injecting drug users, people just beginning to inject drugs, and people with medically acquired hepatitis C);
- partnerships between gastroenterologists and infectious diseases physicians, between these specialists, general practitioners and sexual health services, and between specialists, general practitioners and people with hepatitis C;
- intersectoral partnerships between health services and correctional services (adult and juvenile), community services, non-government organisations providing community services, Aboriginal and Torres Strait Islander services, Indigenous communities, and education authorities—a wide range of bureaucracies need to take responsibility for hepatitis C within their domains;
- the partnership between governments, affected people and the community at large (including the families and friends of people with hepatitis C)—there is an urgent need to engender greater community compassion for the hepatitis C-affected population, flowing from a better understanding of the situation and wider ownership of it. In the long term, a more humane legal framework for responding to illicit drug taking and associated crime needs to be developed, supported by a greater community will to confront the underlying social problems leading to drug use and the provision of a range of treatment and harm-minimisation options. This involves partnership between the health and justice systems (including the police);
- within whatever model is finally adopted, partnership between the hepatitis C strategy and alcohol and drugs strategies, at Commonwealth, State and Territory, and community sector levels, encompassing advisory, bureaucratic and community-based roles;
- political partnerships, energised through a multi-faceted approach to health, drugs and crime-related problems affecting society as a whole—a bipartisan approach at national and State and Territory levels.

Recommended directions and priorities

A number of strategies are central to the extension of partnerships: commitment; capacity building; use of a primary health care approach; building sustainable intersectoral partnerships; and integrating effort.

Commitment

- Make a commitment to extending the partnership approach as a means of mobilising a broader range of participants in the response to hepatitis C.

Capacity building

- Develop strategies to build the capacity of community organisations representing affected communities and to broaden the focus of the partnership beyond current injecting drug users.

A primary health care approach

- Define the elements of a primary health care approach and how this would be facilitated, building on work already done by the Royal Australian College of General Practitioners, people with hepatitis C, divisions of general practice, and State and Territory governments (for example, the New South Wales demonstration projects).

Building sustainable intersectoral partnerships

- Initiatives to build sustainable intersectoral partnerships need to be part of the national and State and Territory strategies to reduce transmission of hepatitis C. The proposed national strategy document could provide a guiding framework.

Integrating effort

- Create a partnership to integrate efforts in public health, drug strategy and law reform, initially in relation to the challenge posed by hepatitis C.

1.5.5 Challenge 5—clarifying structures, roles and responsibilities

If structures, roles and responsibilities are clarified it will be easier to create the right environment for meeting the challenges hepatitis C presents for Australia.

The Commonwealth, the States and Territories, medical and health care professionals, professional colleges and associations, research bodies, non-government organisations, and volunteers all have roles. Among the most important organisations are

- the Australian National Council on AIDS and Related Diseases (including its Hepatitis C Sub-committee)
- the Intergovernmental Committee on AIDS and Related Diseases
- the Australian National Council on Drugs
- the Intergovernmental Committee on Drugs
- the Australian Hepatitis Council

- the Australian Intravenous League
- Haemophilia Foundation Australia.

The medical profession, particularly the Gastroenterology Society of Australia, has played a longstanding and vital advocacy role in according greater priority to hepatitis C treatment and care services. More recently, the Royal Australian College of General Practitioners and individual divisions of general practice have been active in the development and promotion of shared-care models.

Many of those who were interviewed claimed that, although structures and mechanisms exist, what has been lacking is a clear sense of direction and, most importantly, the will to make things happen. Lacking too has been the sense of momentum usually associated with an effective national response.

The Commonwealth's leadership role is changing, but it is generally acknowledged that the Commonwealth is in a good position to bring parties together to resolve major problems.

The current national advisory structures—ANCARD and IGCARD—are considered effective within the existing model. Collaboration and coordination of education and prevention activities across jurisdictions are promoted by the IGCARD Hepatitis C Education and Prevention Working Group. ANCARD has been responsible for a number of important initiatives, including securing \$1.7 million for research specific to hepatitis C and other national programs. Its national leadership role in relation to hepatitis C has been enhanced in recent times by the establishment of the Hepatitis C Sub-committee, although the lack of resources available to the Sub-committee has posed difficulties. It is clear, however, that an up-to-date strategy document, dealing with current needs and challenges, is urgently needed.

The diverse nature of groups infected with hepatitis C poses a complex challenge for community organisations attempting to meet a range of needs. Where hepatitis C councils have been established, they appear to have provided an important avenue for people to gain information about hepatitis C without the stigma associated with HIV or injecting drug use. Further support for user groups and hepatitis C councils in carrying out their respective roles is warranted.

The National Public Health Partnership has the potential to be an integrating mechanism for tackling problems such as hepatitis C that cross different national strategies. The restructuring of the National Drug Strategy advisory committees to mirror those associated with HIV/AIDS and related diseases should allow for more effective community involvement in the Strategy and closer collaboration in relation to communicable diseases.

Further, if we are to achieve a more effective national response to hepatitis C, the question of sufficient resources must be dealt with. Much has been achieved by using pre-existing non-hepatitis C programs and adapting them to accommodate hepatitis C. But the use of existing infrastructure has limited the amount of additional funds that have been allocated to deal with hepatitis C.

The broadbanding of Commonwealth public health funding to the States and Territories presents an opportunity for jurisdictions to direct additional funds to hepatitis C if they decide the epidemic warrants higher priority than other areas. There is an expectation that this will occur in time. Renegotiation of the Public Health Outcome Funding Agreements in 1999 offers the opportunity to introduce outcome measures specifically relevant to hepatitis C.

It would, however, be unrealistic to expect that the challenges outlined in this chapter might be met without additional funding by both the Commonwealth and the States and Territories. The limited availability of funds for dealing with hepatitis C has undoubtedly constrained responses to the epidemic in all jurisdictions.

Recommended directions and priorities

Possible models for responding to hepatitis C are discussed in Section 1.6, although the reviewers make no recommendations about the detail of future advisory structures. Irrespective of the model adopted, though, the following elements are essential: coordination structures; a new blueprint for a national response; funding; monitoring mechanisms; integration with the National Drug Strategy; and further support for community-based organisations.

Coordination structures

The current national advisory structures—Australian National Council on AIDS and Related Diseases and Intergovernmental Committee on AIDS and Related Diseases—are effective and their functions connected with hepatitis C need to continue. ANCARD's Hepatitis C Sub-committee has given impetus to the national effort, and it is essential to retain a group of hepatitis C experts with a dedicated brief. It may, however, be worth considering whether everything possible is being done to facilitate participation by representatives of the affected communities (see challenge 4—Section 1.5.4). Advisory mechanisms at State and Territory level are also essential to a comprehensive national response.

A new blueprint for a national response

Again, whatever model is adopted, a new, up-to-date strategic document on hepatitis C is required, to provide a framework within which all jurisdictions, including the Commonwealth, can develop their more detailed responses, using action plans for the triennium. Endorsed by Ministers responsible for health, the document should be conceptually based and provide a blueprint for action. It should be an authoritative guide to best practice in responding to the epidemic, using the available evidence to identify the areas in which effort should be focused for greatest gain.

Such a document would be consistent with the focus on attaining goals, rather than on the detail of how these goals might be realised. The latter would be covered in individual action plans, which would also describe how resources were to be designated.

Funding

Although funds that could be used for hepatitis C flow through the Public Health Outcome Funding Agreements, it will be necessary for each jurisdiction to determine

how it might finance an enhanced response to hepatitis C. There are four ways in which additional funding for dealing with the epidemic could be obtained:

- re-allocation of public health funding from other areas that are of a lesser priority;
- allocation of additional funds from within the broader funds under the control of health departments (not just public health funds);
- allocation of additional funds from treasuries if increased current expenditure on prevention and treatment can be justified on the basis of potential future savings—this concept is known as ‘measure and share’. The findings of the economic analysis could be used to promote this argument;
- allocation of new funds linked to a specific set of hepatitis C-related initiatives.

The extent to which any of these options are taken up, if at all, will largely depend on decisions about relative priorities.

Monitoring mechanisms

Monitoring mechanisms, probably using existing structures, are necessary, at both Commonwealth and State and Territory levels. Use could be made of the monitoring mechanisms established by IGCARD and the National Drug Strategy, which will be informed by developments resulting from the work of the National Public Health Partnership's Planning and Practice Working Party. Individual jurisdictions, including the Commonwealth, would need to monitor implementation against their action plans as well as monitoring progress towards the attainment of goals. At the national level, however, the focus of any monitoring mechanism would be twofold: reviewing progress towards outcomes and targets; and supporting the Partnership by identifying and overcoming obstacles.

Integration with the National Drug Strategy

Words such as ‘linkage’ are often used to describe the connection of programs or services so that they work together. But ‘linkage’ suggests passivity: something much more active is needed in this case. Integration is a challenge that, like any other challenge, requires commitment, planning, agreed outcomes and, importantly, accountability.

The National Public Health Partnership might consider some additional initiatives in promoting integration between the National Drug Strategy and the model chosen for the future national response to hepatitis C. An Integration Working Party, consisting of representatives of both policy areas, could be established to identify areas for greater collaboration and consistency, so that the strategies enhance and support one another. This may also need to be reflected at the State and Territory level.

One way of thinking about integration might be to think in terms of the principal points of intersection between the two strategies, where a more coordinated approach could be mutually beneficial. For instance, in targeting the ‘community at risk’—current and potential injecting drug users—both strategies will have programs, activities and messages that should be aligned. The same applies to educating the ‘general community’—including parents and schools—about appropriate responses to drug use.

Because hepatitis C has been managed in the context of AIDS and related diseases, the response to hepatitis C has evolved as a disease-management rather than a drug use response. Hepatitis C can be viewed through either 'window' (disease or drug use) but the reality is that an integrated approach—whereby matters associated with communicable diseases are seen as central to the National Drug Strategy, not peripheral to it—is necessary.

Further support for community-based organisations

Further support for user organisations and hepatitis C councils—so that they can carry out their roles with increased reach and without duplication—is important, especially for organisations representing injecting drug users, given their potential for marginalisation.

1.6 Models for a strategic response

There is consensus among those with an interest in the problems associated with hepatitis C that a revised strategic approach is required if we are to confront the challenges now being posed by the epidemic and give momentum to Australia's response. Such an approach must be national, so the reviewers have considered at length ways of organising a more coherent strategic approach to hepatitis C and the model to support it. Options for such a model range from taking a disease-specific approach to integrating hepatitis C-related strategies with those applicable to other communicable diseases.

Although each of the models would have significant implications for how Australia responds to the hepatitis C epidemic, dedicated funding would not be an element since Commonwealth public health funding has now been broadbanded. Nor would the States and Territories necessarily be bound to replicate the national model.

Dealing with the problem of injecting drug use, which comes within the framework of the National Drug Strategy, will be of vital importance to the success or otherwise of Australia's response to hepatitis C. It is therefore essential that integration between the National Drug Strategy and initiatives designed to redress the hepatitis C problem be improved. This is a given for each of the possible models.

There are three possible models within which the overall strategic response to hepatitis C could be located: separate hepatitis C and HIV/AIDS strategies; further development of the 'HIV/AIDS and related diseases' approach; and a communicable diseases framework that takes in specific sub-strategies.

1.6.1 Model 1—separate hepatitis C and HIV/AIDS strategies

A model involving separate hepatitis C and HIV/AIDS strategies would see the abandonment of the 'HIV/AIDS and related diseases' approach. It would be replaced by two separate, disease-specific strategies that fully describe the approaches to be taken to meet the particular challenges of each disease.

1.6.2 Model 2—further development of the ‘HIV/AIDS and related diseases’ approach

Further developing the current ‘HIV/AIDS and related diseases’ approach would involve setting out clear directions in relation to hepatitis C as well as HIV/AIDS. It would also provide the opportunity to incorporate sub-strategies, or strands, relating to other areas such as sexually transmissible diseases and Indigenous Australians’ health. An alternative approach—still using this general framework—would be to have sub-strategies, or strands, built around population groups rather than diseases.

1.6.3 Model 3—a communicable diseases framework that takes in specific sub-strategies

This model would require the development of a broad framework to guide the national response to all communicable diseases of public health significance. The framework would incorporate goals, objectives, principles, and broadly delineated roles and responsibilities. Because specific strategies need to be adopted for different types of communicable diseases, or population groups at potential risk for particular diseases, the framework would also have to accommodate separate strands, or sub-strategies.

These sub-strategies, could be built around particular communicable diseases, groups of similar diseases, or population groups. The disease groups might be blood-borne viruses, sexually transmissible diseases, food-borne diseases, vaccine-preventable diseases, diseases spread by casual contact, and so on. The population groups might be Indigenous Australians, injecting drug users, homosexually active men, young people, the general community, particular ethnic groups, and so on. Accounting for these separate strands would determine the approach to be taken to particular diseases.

1.6.4 Criteria for assessing the models

The various models could be assessed by applying the following criteria.

- coordination—does the model promote coordination across the range of interests at national and State and Territory levels?
- how best to respond to the challenges posed by hepatitis C and HIV/AIDS—does the model give sufficient priority to hepatitis C without losing sight of the bigger picture?
- sensitivity to population groups and their needs—does the model allow for the full involvement of affected communities and constituencies to ensure relevance and sustainability?
- efficiency—does the model allow for greater efficiencies through optimising the use of expertise across diseases (where relevant and beneficial) and streamlining infrastructure development in areas such as surveillance, monitoring and evaluation?

- transparency in priority setting—does the model allow for greater transparency in decision making relating to the priorities accorded particular diseases?
- flexibility—does the model provide a broad framework for responding to emerging trends in communicable diseases without it being necessary to establish dedicated infrastructure each time a new epidemic emerges?
- sustainability—does the model promote sustainability over time; for example, through progressive building of collaborative relationships?
- consistency with public health policy directions—does the model draw together public health effort into a more integrated system that has the capacity to act on established problems and to anticipate and respond to emerging ones?

1.6.5 Choosing the model

The challenge in developing and implementing an integrated approach involves on one hand maintaining support for the priorities of designated or vertical strategies while on the other hand managing coordination in a way that enhances the capacity for cooperation. If care is taken to develop an integrated approach that takes account of the need for disease-specific responses, integration will not result in the loss of focus associated with vertical programs. At the same time, the considerable benefits of a more coordinated and integrated approach can be realised. Accordingly, the reviewers recommend consideration of either model 2 or model 3.

The establishment of a communicable diseases framework—as outlined in model 3—would quite probably take some time, thus distracting attention from developing a more effective national response to hepatitis C. A staged approach to the framework's development would involve developing at least the basis of the overall framework (principles, surveillance mechanisms, and so on) and the strands, or sub-strategies, relating to hepatitis C and HIV/AIDS. Development of strands for other communicable diseases could follow. Another possibility would be to adopt model 2, with the intention of working towards an overall framework for communicable diseases.

At a national mid-review consultation workshop involving about 50 interested parties, it became evident that majority opinion favoured the development of a communicable diseases framework that can embrace hepatitis C and other diseases as specific sub-strategies—the model 3 proposal. It was acknowledged that the development of such a framework will take time and that this goal should be pursued progressively.

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2 The review and the methodology

2.1 The National Hepatitis C Action Plan

In 1998 the Commonwealth Department of Health and Aged Care commissioned this review of the National Hepatitis C Action Plan and the associated Nationally Coordinated Hepatitis C Education and Prevention Approach. The Action Plan was developed by the Commonwealth and agreed to by all States and Territories at the October 1994 meeting of the Australian Health Ministers Advisory Council. The document detailing the Education and Prevention Approach was released in November 1995, having been developed by an AHMAC reference group; it is seen as integral to the Action Plan and any references to the Action Plan in this document refer also to the Education and Prevention Approach.

2.2 The terms of reference for the review

The terms of reference for the review are as follows:

1. Present a strategic overview of the hepatitis C epidemic in Australia including:
 - a. estimates of hepatitis C incidence and prevalence in Australia, projections of the long-term sequelae of hepatitis C infection, estimates of present and future economic costs of hepatitis C to Australia, and a commentary on the social impact of hepatitis C;
 - b. deficiencies in information collection and research capacity in achieving 1(a); and
 - c. priorities for future effort in remedying these deficiencies.
2. Assess the performance of the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach in relation to their policies, principles and objectives across its major areas of activity:
 - epidemiology and surveillance;
 - education and prevention programs;
 - testing strategy; and
 - patient management, counselling and treatment.
3. Identify the strengths and weaknesses of the current national and state level responses to hepatitis C and the opportunities and threats facing these responses. This analysis should include consideration of the national liaison and coordination mechanisms linking hepatitis C with HIV/AIDS, the National Drug Strategy and other public health activities.
4. Consider and discuss the implications of the changing public health policy context since the National Hepatitis C Action Plan was first developed, including:

- the development of the National Public Health Partnership;
 - changes to Commonwealth–State relations, including the broad-banding of Commonwealth public health program Specific Purpose Payments to State and Territory governments;
 - the development and implementation of the third National HIV/AIDS and Related Diseases Strategy;
 - developments in national drug policy; and
 - the development of the National Communicable Diseases Surveillance Strategy.
5. Recommend strategic directions and priorities for national action on hepatitis C including specification of the essential components of an organised response to hepatitis C at the State and Territory level.

2.3 Components of the review

Different components of the review were undertaken by different individuals or organisations:

- history of hepatitis C national policy development—Evaluation and Research Unit, Population Health Division, Commonwealth Department of Health and Aged Care, with sections written by Mr Jeff Ward and Mr Alex Wightman;
- epidemiological estimates—National Centre in HIV Epidemiology and Clinical Research;
- review of global epidemiology and international public health responses—National Centre in HIV Epidemiology and Clinical Research;
- estimates of present and future economic costs—Mr Alan Shiell, Department of Public Health, University of Sydney;
- the personal and social impact of a hepatitis C diagnosis—Mr Justin Rowe, former Chair, Hepatitis C Council of Victoria;
- review of Action Plan implementation—Evaluation and Research Unit, Population Health Division, Commonwealth Department of Health and Aged Care;
- analysis of strengths and weaknesses, opportunities and threats in Australia's response to hepatitis C—David Lowe Consulting and Mandala Consulting;
- strategic directions and priorities for national action—David Lowe Consulting and Mandala Consulting;
- models for a strategic response—David Lowe Consulting and Mandala Consulting;
- summary and overview—David Lowe Consulting and Mandala Consulting;
- update of progress towards the development of a hepatitis C vaccine—Dr Scott Bowden and Professor Stephen Locarnini, Victorian Infectious Diseases Reference Laboratory.

The chapters on the epidemiology of the hepatitis C virus and the analysis of economic data are summaries of work done in these areas. The full versions of these chapters are available from the Commonwealth Department of Health and Aged Care's website (<http://www.health.gov.au>).

2.4 Methodology

2.4.1 Scope

Although the focus of the review was the National Hepatitis C Action Plan, it is recognised that Australia's response to hepatitis C goes beyond the recommendations contained in the Action Plan. Accordingly, the reviewers adopted a broad approach, particularly taking into account the implications of the changing public health policy context since the development of the Action Plan. There have been two especially notable developments: incorporation of hepatitis C in the National HIV/AIDS Strategy 1996–97 to 1998–99 as a related disease; and the formation of the National Public Health Partnership.

Details of the methodology for particular components of work are generally provided in the relevant chapter. In the case of the chapters on the Australian epidemiology of hepatitis C and the economic analysis, the methodology used is apparent from the full versions of these documents, which, as noted, are available from the Department's website.

2.4.2 Consultation

Extensive consultation with interested individuals and groups was central to the review. The consultation process had five main elements.

- An Advisory Committee representing a diverse range of expertise met regularly to discuss the review methodology and results. Members of the Advisory Committee are listed in Section 2.4.3.
- An advertisement calling for submissions was placed in the national press. In addition, an invitation to present a submission was sent to a wide range of interested groups. Individuals and groups that presented submissions are listed in Appendix A.
- Interviews were held in each State and Territory and with Commonwealth officials.
- The Commonwealth Department of Health and Aged Care conducted surveys of all jurisdictions and community-based organisations to determine attitudes to implementation of the Action Plan.

A national mid-review meeting of interested parties was held to consider findings in the areas of epidemiology, economic analysis, implementation of the Action Plan, the challenges that had been identified, proposed directions for the future, and models for a response to hepatitis C.

2.4.3 The Advisory Committee

An Advisory Committee made up of the following people was established to provide advice to the review:

Dr Andrew Penman (Chair)
Chief Executive Officer
New South Wales Cancer Council
(formerly Director of Disease Prevention and Health Promotion, New South Wales Health Department)

Professor Bob Batey
Director
Gastroenterology Department
John Hunter Hospital

Dr Jim Butler
National Centre for Epidemiology and Population Health
Australian National University

Mr Brendan Gibson
Director
Evaluation and Research Unit
Public Health Planning Branch
Commonwealth Department of Health and Aged Care

Ms Michelle Kosky
Chair
Hepatitis C Sub-committee
Australian National Council on AIDS and Related Diseases

Dr Lewis Marshall
Medical Coordinator
Communicable Diseases Control Program
Health Department of Western Australia

Mr Eamonn Murphy
Director, HIV/AIDS Hepatitis C Section
Commonwealth Department of Health and Aged Care

Dr Aileen Plant
Department of Public Health
University of Western Australia

Mr Jeff Ward
President
Australian Hepatitis Council

Mr Jack Wallace

former Chair

Intergovernmental Committee on AIDS and Related Diseases Hepatitis C Education
and Prevention Working Group

Mr Steven Hall

Royal Australian College of General Practitioners

Mr Alex Wightman

Australian Intravenous League

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Part Two

The nature of the problem

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3 Epidemiology of the hepatitis C virus

This chapter summarises the document entitled *Estimates and Projections of the Hepatitis C Virus Epidemic in Australia*, by the Hepatitis C Virus Projections Working Group, which was convened in 1998 under the auspices of the Hepatitis C Sub-committee of the Australian National Council on AIDS and Related Diseases. The document in its entirety is available via the Commonwealth Department of Health and Aged Care's website (<http://www.health.gov.au>).

3.1 The hepatitis C virus

The hepatitis C virus was first reported in 1989 and a serological (antibody) assay became available in February 1990.

The virus is a single-stranded RNA virus of the family Flaviviridae. At least six genotypes of the virus exist. Concurrent infection with different genotypes is possible, and it is possible for re-infection to occur after complete resolution of a previous infection with the same genotype. Genotypic variations may play a role in the differences in disease progression and the response to interferon therapy.

3.1.1 Infection

It is unusual to develop any serious illness at the time of infection with the hepatitis C virus. Many active infections are asymptomatic and people can remain healthy. Some people do, however, develop a flu-like illness in which nausea may be the predominant symptom. Other common symptoms are extreme tiredness, abdominal and back pain, and headache. Jaundice may develop, but it is not common. In symptomatic patients the incubation period usually ranges from six to 10 weeks.

It is thought that 80 per cent of people who are exposed to the hepatitis C virus become chronically infected and are able to transmit the virus. For the majority of these people, though, such chronic infection is asymptomatic. When symptoms are evident they are generally non-specific and include general malaise, right upper quadrant abdominal discomfort, and anorexia. Spontaneous viral cure in chronic patients is thought to be rare.

Cirrhosis may develop in up to 20 per cent of people with chronic hepatitis C virus infection: this generally occurs at least 20 years after the time of infection. Even if cirrhosis develops it may run an indolent course. Some patients will develop liver failure. A proportion of those who develop cirrhosis resulting from chronic hepatitis C virus infection ultimately develop liver cancer.

Acute infection with the virus generally elicits an antibody response to several of the structural and non-structural viral proteins. It is thought, however, that the antibodies produced are not protective. Patients should be advised that, even in the event of confirmed virological cure of acute hepatitis C virus infection, re-infection with the virus may result in symptomatic or chronic infection, or both.

3.1.2 Transmission

The hepatitis C virus is primarily transmitted through blood-to-blood contact. Sharing of injecting equipment by drug users is the most common route of transmission in Australia: a single episode of sharing may result in infection. Sharing needles and syringes, tourniquets, spoons, water, filters and solvents may lead to transmission.

Transfusion of blood was a source of transmission of the virus before blood screening was introduced in February 1990. Since then transmission via this route has been dramatically reduced, although not completely eliminated. There is some risk of infection from apparently uncontaminated blood because it takes two to three months after infection for a detectable blood antibody level to develop. Recipients of pooled blood products (for example, Factor VIII) collected in Australia are no longer at risk of infection because these products are now heat-treated to destroy the virus.

Tattooing is a proven method of transmission of the hepatitis C virus. A similar risk is associated with other body-piercing activities, such as acupuncture and ear piercing, if equipment is not sterile.

The virus can also be transmitted in a health care setting; for example, through a health care worker being exposed to an infected person or another infected source or through transmission from health worker to patient or from patient to patient.

Sexual activity poses a very low risk of transmission, although it does seem that transmission can occur.

Antibodies to the hepatitis C virus are transmitted from an infected mother to her child but they disappear from the infant's circulation within 12 months of birth. There is also a small risk of transmission of the virus from mother to child: about 5 per cent of children born to hepatitis C-infected mothers have been found to have acquired the infection. No cases of transmission through breastfeeding have been reported, although this has been little studied.

There is published evidence that the virus may be transmitted through the sharing of razors. The sharing of combs or toothbrushes has not been shown to be important epidemiologically, but the potential for transmission remains. There is no evidence to suggest that mosquitoes and other blood-feeding insects transmit the virus.

3.1.3 Treatment

Interferon alpha is currently the only drug approved for the management of chronic hepatitis C. It is available under section 100 of the *National Health Act 1953* for the treatment of patients who meet specific criteria. Treatment will be initiated and directed by a gastroenterologist or hepatologist at an approved liver clinic, although management may be shared with appropriately qualified general practitioners.

Interferon therapy has a limited rate of success: only about a third of those receiving it clear the virus at the end of the therapy. It has recently been approved for 12 months' therapy, which is expected to increase the therapy's effectiveness. Interferon alpha

commonly produces side-effects such as depression, fever, chills, myalgia, fatigue, nausea, anorexia, diarrhoea, insomnia, irritability and alopecia. Depression can be severe and of relatively sudden onset. Loss of white blood cells and decreased ability to coagulate can also occur.

Interferon has been trialled in combination with ribavirin and the benefits of the combination are now documented. Poynard et al. (1998), McHutchison et al. (1998) and Davis et al. (1998) report on treatment naïve and treatment relapse which document this benefit for the two groups. Efforts are underway to make this the standard treatment protocol and the reviewers support these moves. A panel of experts convened by the American Food and Drug Administration has recommended that ribavirin be approved for the treatment of people with hepatitis C, but there are reports of serious side-effects associated with it, among them fatal heart attacks in older people. There is also some evidence that long acting interferon may improve treatment.

3.2 Surveillance

Over 110 000 hepatitis C diagnoses have been reported to Commonwealth and State notification systems for the period 1991 to 1997. Of notifications to the National Notifiable Diseases Surveillance System, 67 to 78 per cent were in the age range 20 to 39 years, with a male-to-female ratio of 1.6–1.7:1.0.

3.2.1 Risk factors

Table 3.1 summarises studies examining the risk factors for hepatitis C virus infection in Australia. The study results suggest that about 80 per cent of all hepatitis C infections have occurred as a result of injecting drug use. Tattooing, receipt of blood products or blood transfusions, immigration to Australia from countries with a high hepatitis C prevalence, and other transmission sources account for the remainder of infections.

3.2.2 Prevalence

Several studies have examined the prevalence of hepatitis C in populations of injecting drug users; these are summarised in Table 3.2. Taken together, the study results show that the prevalence of hepatitis C among regular injecting drug users in Australia has been consistently over 50 per cent since the early 1970s.

The generally very high prevalence of hepatitis C among injecting drug users would seem to indicate that the virus has been present among this population for some decades—long enough to reach endemicity. The continuing high rates of transmission of the virus among injecting drug users—when the spread of HIV and hepatitis B seem to be controlled—demands explanation. First, the prevalence of hepatitis C virus infection in Australia is such that about 50 per cent of current injecting drugs users will be infected; this compares with less than 2 per cent of injecting drug users being infected with HIV or hepatitis B. Very infrequent behaviour allowing transmission of

blood-borne viruses is sufficient to maintain a high rate of transmission of hepatitis C. Second, a person infected with hepatitis C has relatively higher concentrations of infectious particles in their blood compared with HIV concentrations in the blood of an HIV-infected person for most of the course of the infection. This means that a much smaller amount of blood would be necessary to carry an infectious dose of hepatitis C. Both these factors can explain the continued high rate of hepatitis C virus transmission simply because of continued sharing of needles and syringes, even though the rate of sharing injecting equipment has decreased. The decreased rate of sharing injecting equipment appears, however, to have been sufficient to substantially decrease the transmission of HIV and hepatitis B virus in the same populations.

Table 3.3 summarises studies estimating hepatitis C prevalence among populations other than injecting drug users in Australia. The prevalence rate was around 1 per cent in antenatal patients, first-time blood donors and health care workers. Rates were higher in renal transplant recipients and dialysis patients and much higher in people who had received blood or blood products before screening tests became available. Rates were also higher among prison entrants, reflecting the relationship between prisoners and injecting drug use.

3.2.3 Incidence

The incidence of hepatitis C among repeat blood donors in Victoria has been estimated at 1.9 per 100 000 (Whyte & Savoia 1997). Table 3.4 summarises studies of the incidence of hepatitis C virus infection among injecting drug users.

In a combined analysis based on two cohorts of injecting drug users in Melbourne and one in Sydney, the incidence of hepatitis C infection in the 1980s and early 1990s was estimated to be around 15 infections per 100 person-years of follow-up, which is consistent with the results of other studies of hepatitis C incidence among injecting drug users in Australia. The analysis found that incidence was higher among drug users who started injecting before 1987 compared with those who started injecting in 1987 or later (18 as opposed to 13 infections per 100 person-years; $p < 0.31$). Even though this decrease in incidence was based on a small number of cases and was not statistically significant, it did coincide with the introduction of the needle and syringe exchange program and other preventive campaigns primarily aimed at reducing HIV infection among injecting drug users. In the Melbourne study, hepatitis B incidence was also higher among drug users who started injecting before 1987 compared with those who started injecting in 1987 or later (12 as opposed to four infections per 100 person-years; $p < 0.0001$), providing further evidence of a reduction in the transmission of infectious disease among injecting drug users (Crofts et al. 1997).

Table 3.1 Risk factors for hepatitis C in Australia

Population	Site	Year	Number	IDU	Tattoo	Blood	Other	Reference
				(per cent)				
Hepatitis C notifications	Northern New South Wales	1993–94	467	85	6	8	8	Sladden et al. (1997)
Incident hepatitis C notifications	Queensland	1994	532	77	3	6	14	Slevey et al. (1996b)
	Australian Capital Territory	1994	154	81	3	8	9	
	Northern Territory	1994	57	64	11	7	17	
Incident hepatitis C notifications	All States and Territories	1995	116	91	–	1	8	Andrews & Curran (1996)
Antenatal patients	Adelaide	1995	17	71	–	–	–	Garner et al. (1997)
Blood donors	Sydney	1990–91	220	47	10	7	35	Kaldor et al. (1992)
Liver clinics	Melbourne	1990–93	342	51	155	6	275	Strasser et al. (1995)
	Sydney	1990–95	619	75	25		25	Li et al. (1998)

– Zero.

Table 3.2 Prevalence of hepatitis C antibody among populations of injecting drug users in Australia

Population	Site	Source	Year	Prevalence		Reference
				%	Number	
Hospital inpatients	Victoria	Fairfield Hospital	1971	57	44	Moaven et al. (1993)
Hospital inpatients and outpatients	Victoria	Fairfield Hospital	1971–89	62	431	Fairley et al. (1990)
Methadone clients	Sydney	Westmead Hospital	1986–89	86	172	Bell et al. (1990)
Hospital inpatients	Geelong	Geelong Hospital	1989	47	17	Williamson et al. (1990)
All prison entrants	Victoria	Victorian prisons	1991–92	65	1562	Crofts et al. (1994)
STD clinic	Adelaide	Clinic attenders	1991–93	30	989	Waddell (1994)
Methadone clients	South Australia	Clinic attenders	1992–93	94	87	Gaughwin et al. (1994)
Broad spectrum	Victoria	Field recruits	1990–95	62	519	Crofts & Aitken (1997)
Primary care (Kirketon Road Centre)	Sydney	Clinic attenders	1992–95	45	1078	van Beek et al. (1998)
Methadone clients	Melbourne	Clinic attenders	1991–95	67	1741	Crofts et al. (1997a)
Young IDUs	Perth	Field recruits	1993	8	75	Loxley (1992)
Methadone clients	Brisbane	Clinic attenders	1994	69	260	Selvey et al. (1997)
Needle exchanges	South-east Queensland	Exchange attenders	1994	34	268	Selvey et al. (1996a)
Broad spectrum	Sydney	Field recruits	1994	71	139	Loxley et al. (1995)
	Perth			41	76	Butler et al. (1997)
	Adelaide			51	102	Louie et al. (1998)
	Melbourne			57	115	Thompson et al. (1998)
	Sydney	Long Bay	1994	66	206	MacDonald (1998)
Vietnamese communities	Melbourne	Field recruits	1995	100	27	
Juvenile centre residents	Melbourne	MJJC	1995 (?)	36	53	
Needle exchanges	All States and Territories	Exchange attenders	1995	63	979	
			1996	66	1453	
			1997	50	1704	
Prison inmates	New South Wales	New South Wales prisons	1996	73	328	Butler (1998)
Methadone clients	New South Wales,	Clinic attenders	1996	69	326	NCHECR (1997)
	Queensland, South Australia, Western Australia					

1. Testing with in-house non-specific peptide assay.
2. Self-reported hepatitis C status.

Table 3.3 Prevalence of hepatitis C antibody among populations other than injecting drug users in Australia

Population	Site	Source	Year	Prevalence		Reference
				%	Number	
Antenatal patients	Victoria	Provincial hospital	1989	0.4	252	Fairley et al. (1990)
Geelong	Geelong	Geelong Hospital	1990	3	99	Williamson et al. (1990)
	Adelaide	Lyell McEwin	1995	1.1	1537	Garner et al. (1997)
Blood donors	Western Australia	Donations	1987–89	0.7	1843	Ismay et al. (1995)
	New South Wales	Donations	1987–89	0.8	1592	Ismay et al. (1992)
	Geelong	Donations	1990	0.4	280	Williamson et al. (1990)
	Sydney	All donations	1990–91	0.4	217020	Archer et al. (1992)
First-time donors	Melbourne	All donations	1994	0.05	–	MRCBTS, unpublished
	Brisbane	Donations	1994–95	0.5	34725	Mison et al. (1997)
	Melbourne	Two hospitals	1989	6.9	261	Williamson et al. (1990)
Renal transplants	Melbourne	Two hospitals	1989	5.9	205	Williamson et al. (1990)
Dialysis patients	Melbourne	Two hospitals	1989	5.9	205	Williamson et al. (1990)
Haemophiliacs	Melbourne	Patients	1987–89	75.6	176	Williamson et al. (1990)
Prisoners	Victoria	All entrants	1991–92	39	3269	Crofts et al. (1995 ¹)
	Victoria	Non-IDU entrants	1991–92	16	1712	Crofts et al. (1995 ¹)
	Sydney	All entrants	1994	37	408	Butler et al. (1997)
	Sydney	Non-IDU entrants	1994	7.3	192	Butler et al. (1997)
	New South Wales	Inmates	1996	58	438	Butler (1998)
	New South Wales	Non-IDU residents	1996	12	105	Butler (1998)
Juvenile centre	Melbourne	All residents	1995	23	83	Crofts et al. (1998)
	Melbourne	Non-IDU inmates	1995	0	30	Crofts et al. (1998)
Health care workers	All jurisdictions except Northern Territory	Tested following occupational exposure	1995–97	0.7	2571	MacDonald (1998)

1. Testing with in-house non-specific peptide assay.

Table 3.4 Incidence of hepatitis C among injecting drug users in Australia

Population	Year	Seroconverters	Incidence per 100 person-years			Reference
			%	Number	(95% CI)	
Prisons entrants, Victoria	1991–92	8	(17%)	38.2	(19.1, 76, 4)	Crofts et al. (1995)
STD clients 'ever injected', Adelaide	1991–93	2	(3%)	38.2	(0.4, 12.7)	Waddell (1994)
Methadone clients, South Australia	1991–93	1	(33%)			Gaughwin et al. (1994)
Field-recruited IDUs, Victoria	1990–91	5		16.6	(6.9, 40.0)	Crofts & Aitken (1997)
	1992–93	8		10.9	(5.5, 21.8)	
	1994–95	6		8.1	(3.6, 18.0)	
People attending Kirketon Road Centre	1992–93	12	(13%)	18.9	(8.2, 29.5)	Van Beek et al. (1998)
	1994–95	19	(15%)	22.5	(12.4, 32.6)	
Methadone clients, Melbourne	1991	2		33.3	(8.3, 133.0)	Crofts et al. (1997a)
	1992	2		10.3	(4.6, 23.0)	
	1993	9		34.0	(18.0, 65.0)	
	1994	6		24.0	(11.0, 53.0)	
Methadone clients, Brisbane	1994–95	5		10.6	(2.0, 20.0)	Selvey et al. (1997)
People attending needle exchanges, all jurisdictions	1995–96	14	(61%)			Macdonald (1998)

3.3 Estimates of the prevalence, incidence and impact of hepatitis C in Australia

As noted, in 1998 the Hepatitis C Virus Projections Working Group was convened under the auspices of the ANCARD Hepatitis C Sub-committee. The Group's task is to develop estimates of the prevalence, incidence and impact of hepatitis C in Australia to enable researchers, educators and policy makers to work from a common set of estimates of the likely long-term health consequences of hepatitis C infection. This work is necessary because there are several methodological problems associated with hepatitis C epidemiology. Primary among the problems is the difficulty of detecting newly acquired hepatitis C infection. Other problems concern difficulty in gaining access to populations at high risk of transmission; the long and variable course of disease progression; and the complex and evolving diagnostic methodology for hepatitis C infection. As a result, direct estimation of hepatitis C prevalence in Australia is uncertain and direct estimates of hepatitis C incidence are not available.

To complement direct estimates of hepatitis C prevalence, the Working Group developed models of the hepatitis C epidemic in Australia. Because the epidemic has been largely a result of injecting drug use, and because most hepatitis C data are available for this population, the models adopted were based on an assumed pattern of injecting drug use in Australia. The estimates of hepatitis C infection thus obtained were then inflated to allow for hepatitis C infection resulting from the receipt of blood or blood products or other transmission routes.

The Working Group's conclusions are summarised in the remainder of this chapter; the full report can be obtained from the National Centre in HIV Epidemiology and Clinical Research (Hepatitis C Projections Working Group 1998). The Group's estimates are used throughout this report. The full versions of this chapter is available from the Commonwealth Department of Health and Aged Care's website (<http://www.health.gov.au>).

3.3.1 Estimates of the number of injecting drug users

The consensus estimate was that there were 100 000 regular injecting drug users in Australia in 1997, with lower and upper limits of 80 000 and 120 000. A 'regular injecting drug user' was defined as a person who has injected an average of 10 times a month for at least 12 months with injecting in most months.

The consensus estimate was that there were 175 000 occasional injecting drug users in Australia in 1997, with lower and upper limits of 120 000 and 210 000. An 'occasional injecting drug user' was defined as a person who has injected at least once in 12 months but not often enough to be considered a regular injecting drug user.

It was estimated that since 1970 there would have been a 12 per cent increase in new regular injecting drug users every year but with 5 per cent of regular drug users ceasing injecting every year. It was estimated that since 1970 there would have been a 17 per cent increase in new occasional injecting drug users but with 10 per cent of occasional drug users ceasing injecting every year.

3.3.2 Estimates of prevalence and incidence

Direct estimates of hepatitis C infection in Australia in 1995 are that between 170 000 and 195 000 people were probably infected with the virus, with lower and upper limits of 130 000 and 230 000. The figures are based on an estimated rate of prevalence among a sample of urban antenatal patients.

The best modelled estimates were as follows.

- The number of people infected with hepatitis C in 1997 was 197 000 (with lower and upper limits of 149 000 and 234 000).
- Hepatitis C incidence in 1997 was 11 000 (with upper and lower levels of 8500 and 13 500).
- Of all hepatitis C infections, 80 per cent were acquired through injecting drugs and 7 per cent through receiving blood; the remaining 13 per cent were acquired in other ways.
- Of all hepatitis C infections acquired in 1997, 91 per cent were acquired through injecting drugs and zero through receipt of blood; the remaining 9 per cent were acquired in other ways.

3.3.3 Estimated infection

It is estimated that about 75 per cent of hepatitis C exposures result in chronic hepatitis C infection in injecting drug users.

- Using direct estimates of hepatitis C prevalence, this would suggest that there were probably between 130 000 and 145 000 people living with chronic hepatitis C in 1995 (with lower and upper limits of 100 000 and 175 000).
- Using modelled estimates of hepatitis C prevalence, this would suggest that there were 147 000 people living with chronic hepatitis C in 1997 (with upper and lower limits of 111 000 and 177 000).

In estimating the number of people with cirrhosis caused by hepatitis C infection, the progression rate to cirrhosis was assumed to correspond to 8 per cent at 20 years after infection (with slower and faster limits of 5 per cent and 10 per cent) and 20 per cent at 40 years after infection (with slower and faster limits of 12.5 per cent and 25 per cent). Estimates of the rate of progression to liver cancer are less certain but were assumed to correspond to 10 per cent of the rate of progression to cirrhosis. Survival following cirrhosis is 91 per cent at five years and 79 per cent at 10 years (Fattovich et al. 1997).

The modelled estimate of people living with cirrhosis caused by hepatitis C infection was 8500 in 1997 (with lower and upper limits of 4000 and 13 000). It should be noted that many, and possibly the vast majority of, people living with cirrhosis could be both asymptomatic and undiagnosed with either hepatitis C or cirrhosis.

The modelled estimate for hepatitis C–induced liver cancer was 80 cases in 1997 (with lower and upper limits of 40 and 130 cases). For all the scenarios modelled, the number of people with liver cancer was estimated to at least double by 2010.

Between 1983 and 1994 the number of cases of liver cancer in Australia gradually increased, from 195 to 418. The Australian Institute of Health and Welfare projected the incidence of liver cancer for 1997 to be 520 cases. The proportion of liver cancer caused by hepatitis C is uncertain but, based on the modelled projections, it is estimated that 15 per cent (with lower and upper limits of 8 and 25 per cent) of liver cancer cases in 1997 were the result of hepatitis C infection.

3.4 Estimates of disease progression

Using the modelled projections, it is possible to estimate long-term disease progression for a group of 11 000 infected individuals, which is the estimated number of Australians who became infected with hepatitis C in 1997.

It is estimated that, of all those infected with hepatitis C, 25 per cent will clear the virus within two to six months of infection. The remaining 75 per cent will develop chronic, long-term hepatitis C. Eight per cent will develop cirrhosis after 20 years, increasing to 20 per cent after 40 years. Eight-tenths of 1 per cent will develop liver cancer after 20 years, increasing to 2 per cent after 40 years. Two per cent will develop liver failure after 20 years, increasing to 5 per cent after 40 years.

Thus, for every 11 000 people infected by hepatitis C it is estimated that

- 2750 will clear the virus;
- 8250 will develop chronic long-term hepatitis C;
- 880 will develop cirrhosis 20 years after infection;
- 220 will experience liver failure 20 years after infection;
- 88 will develop liver cancer 20 years after infection.

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RESUMED

4 Global epidemiology and international public health responses

4.1 Introduction

This chapter presents data on the global epidemiology of and international responses to hepatitis C. It relies on several information sources. Surveillance data and national policy information were sought from public health authorities in the United Kingdom, the United States and Canada. The United Kingdom responded with published studies of hepatitis C surveillance from the Public Health Laboratory Service Communicable Disease Surveillance Centre. The US Centers for Disease Control and Prevention provided its recently developed document entitled *A Prevention Plan for Hepatitis C Virus Infection* (CDC 1998), along with published reviews of the epidemiology of hepatitis C infection in the United States. Health Canada provided guidelines and recommendations for the prevention and control of hepatitis C as well as published medical and epidemiological information.

Much of the European information presented in this chapter is drawn from the European Survey on Hepatitis C undertaken by France's National Public Health Centre—Le Réseau National de Santé Publique (Nalpas et al. 1996). This survey covered the 15 nations of the European Community and consisted of two questionnaires (one to liver disease practitioners and one to public health authorities) designed to evaluate medical practices and public health responses in relation to hepatitis C. Information on national responses in Europe was also obtained from a report to the European Monitoring Centre for Drugs and Drug Addiction—*Improving the Quality and Compatibility of Data Related to Hepatitis B/C and Delta Virus Infections in Drug Users* (Vingoe et al. 1997). This report, prepared by the National Addiction Centre in London, assessed current mechanisms for hepatitis surveillance in selected European countries. Further information was obtained for France from the National Public Health Centre's comprehensive report entitled *Action concertée sur l'épidémiologie de l'hépatite C* (Desenclos & Drucker 1995).

There is limited available information on the epidemiology of hepatitis C in developing countries. Estimated prevalence figures are, however, provided here where possible.

4.2 Global epidemiology

4.2.1 Prevalence and incidence of hepatitis C

Estimates of the prevalence and incidence of hepatitis C in countries around the world have been generated using varying methods. In many countries estimates are predominantly based on screening data from selected groups such as blood donors, who are not representative of the total population: donors are generally perceived as a low-risk population because donor-deferral procedures exclude people at higher risk. Other data are derived from sentinel surveillance of injecting drug users, the population

at greatest risk of hepatitis C infection. In the absence of representative population-based information, many countries have used blood donor and injecting drug user populations to estimate the prevalence of hepatitis C. The lack of reliable epidemiological information may have contributed to the modest public health response in many countries. Table 4.1 shows hepatitis C prevalence estimates for selected countries' blood donor and injecting drug user populations and among the population in general.

Table 4.1 Hepatitis C prevalence in the total population and among blood donors and injecting drug users: selected countries

Country	(per cent)		
	Total population	Blood donors	Injecting drug users
Australia	1.05	0.05–1.00	50–70
Canada	0.80	0.30	47–88
France	1.20		70
Italy	3.20	1.20–1.50	70
United Kingdom	0.30–1.00	0.08–0.55	60–80
United States	1.80	0.30	50–90
Vietnam	1.00–9.00	0.80–20.60	n.a.

n.a. Not available.

Note: Figures are for various years.

Europe

The European Survey on Hepatitis C estimated that there were 2.4 million to 5.0 million hepatitis C infections in the European Community. These figures should, however, be interpreted with caution because only Belgium, France and Spain have derived national estimates based on representative samples of their populations. For Austria, Ireland, Luxembourg and the Netherlands no prevalence data were available, so the estimates were based on the nearest neighbouring country. The Survey results suggest that the pattern of hepatitis C prevalence in Europe graduates from lower in the north to higher in the south. Prevalence of hepatitis C is broadly estimated at less than 0.5 per cent in northern countries (Sweden, Finland, Denmark, the Netherlands, Ireland and the United Kingdom), at 0.5–1.0 per cent in central countries (France, Belgium, Luxembourg, Germany and Austria), and at more than 1 per cent in southern countries (Italy, Spain, Portugal and Greece). Overall, the prevalence of hepatitis C in the European Community was estimated at approximately 0.9 per cent. Finland and Denmark had the lowest prevalence; Italy and Greece had the highest. Neither Italy nor Greece has derived estimates of prevalence based on national surveys, although in Italy large groups of healthy subjects and blood donors have been studied. These studies show that hepatitis C prevalence increases with age (up to 10 per cent) and is higher in the south, where the prevalence among blood donors is 1.5–6.0 per cent. The overall prevalence estimate for Italy is 3.2 per cent; the estimated number of infected people is 1 to 2 million.

Desenclos and Drucker (1995) estimated hepatitis C prevalence in France based on a national survey conducted in 1994 that enrolled more than 6000 randomly selected healthy subjects aged 20 to 59 years from the French social security system. The survey results revealed an estimated hepatitis C prevalence among adults of 1.2 per

cent. This survey also involved testing hepatitis C–positive subjects for hepatitis C RNA and found that 80 per cent were viraemic. Overall, an estimated 500 000 to 650 000 people have been infected with hepatitis C in France and 400 000 to 500 000 of them remain chronically infected.

Hepatitis C prevalence in the United Kingdom has been estimated at 0.3 to 1.0 per cent (Nalpas et al. 1996). No national prevalence survey has been conducted on a representative sample of the population, so this estimate is based on the prevalence observed in blood donors and other selected groups. A study of injecting drug users in Glasgow found that hepatitis C prevalence had fallen since the introduction of needle and syringe exchanges. The decline was greatest in young injectors (from 92 to 29 per cent) and overall prevalence fell from 90 to 77 per cent (Goldberg et al. 1998).

There are also no national estimates of hepatitis C incidence in the United Kingdom. In a retrospective analysis of all repeat blood donors in England, however, over the 1993 to 1995 study period 14 seroconverted to hepatitis C antibody positivity. The overall estimated rate of seroconversion was 0.26 per 100 000 person-years, which corresponds to less than 1 per 450 000 donations (Soldan et al. 1998). It can be seen that incidence is extremely low in this highly selected population.

In Eastern Europe estimates of hepatitis C prevalence are generally higher than in European Community countries. In one study in Romania 4.3 per cent of a sample of 116 blood donors and 3.7 per cent of 132 controls were antibody positive (Antipa et al. 1993). In Hungary 1.8 per cent of a random sample of blood donors were antibody positive (Hejjas et al. 1992).

North America

Hepatitis C is thought to be the most common blood-borne infection in the United States. The Centers for Disease Control and Prevention has estimated hepatitis C prevalence at 1.8 per cent of the population—3.9 million people. These population-based estimates are derived from the third National Health and Nutrition Examination Survey from 1988 to 1994 (Alter 1997a). The Centers has also estimated that there were about 180 000 new hepatitis C infections each year in the United States during the 1980s. It reports further that since 1990 incidence has fallen by 80 per cent, to about 28 000 new infections a year. The reasons for this reported fall are unclear. Infections resulting from blood transfusion and tissue donation became rare from the mid-1980s, when measures to exclude high-risk donors were introduced. But the greatest drop in incidence did not occur until 1989 and after, and the Centers attributes this to unspecified changes in transmission patterns among injecting drug users (Alter 1997a).

Seroprevalence has not been estimated in a representative sample of the Canadian population. There have, however, been studies of selected populations—cornea donors in Ontario, first-time blood donors in 1996, and pregnant women in British Columbia (Tepper 1998). In addition, an expert panel engaged by Health Canada recently estimated hepatitis C prevalence in Canada based on mathematical modelling of all available data. Overall, prevalence was estimated at approximately 0.8 per cent of the population, which corresponds to 240 000 infected people (plausible range 210 000 to 275 000) (Schabas 1998).

South America

Representative population-based studies of the prevalence of hepatitis C in South America are scarce. One study from Brazil compared prevalence in two random samples, one from an urban community and one from a rural community. The prevalence in the urban population was 1.25 per cent compared with zero in the rural population (Silva et al. 1995). In studies of blood donors in Brazil, prevalence ranged from 1.4 to 2.0 per cent (Martins et al. 1994; de Carvalho et al. 1996). A study in which the risk of transfusion-acquired hepatitis C was estimated in Central and South American countries reported prevalence among blood donors ranging from 0.05 per cent in Honduras to 0.94 per cent in Venezuela (Schmunis et al. 1998).

Other developing countries

There is limited information on the prevalence of hepatitis C in the Asia-Pacific region. One study found that prevalence in a number of Asian countries, including Malaysia, Indonesia and China (Li et al. 1997), ranged from 1.0 to 2.5 per cent. Another study found that prevalence in the general population in Ho Chi Minh City was 1 per cent (Kakumu et al. 1998). In 723 serum samples from Western Province in Papua New Guinea hepatitis C prevalence was found to be 4.1 per cent (Yamaguchi et al. 1993).

In South Africa, hepatitis C prevalence among blood donors from the Western Cape region was found to be 0.41 per cent (Tucker et al. 1997).

4.2.2 Risk factors for hepatitis C

The most potent risk factor for hepatitis C infection in industrialised nations is injecting drug use.

In France a case-control analysis based on hepatitis C-positive blood donors, hospitalised women and healthy subjects found that injecting drug use was associated with an almost 30-fold increase in the risk of hepatitis C infection. Other significant risk factors identified in the analysis were previous blood transfusion and unemployment (Desenclos & Drucker 1995).

Overall, studies of injecting drug users in Europe estimate that 50 to 80 per cent of users are infected with hepatitis C (Vingoe et al. 1997). In the United States the prevalence of hepatitis C among injecting drug users is estimated at between 50 and 90 per cent (CDC 1998); the situation is very similar in Canada, where studies report prevalences of between 47 and 88 per cent (Tepper 1998)—see Table 4.1.

Transmission through donated blood is now rare, and the prevalence of hepatitis C in blood donors is low. Before measures were introduced to restrict donors to volunteers at low risk of infection, however, blood transfusion was an important risk factor in industrialised nations. As a consequence, blood transfusion before screening was introduced—around 1990 to 1992 in most countries—remains a significant risk factor. It has been estimated that 90 000 to 160 000 people in Canada were infected with hepatitis C through transfusions of infectious blood or blood components between 1960 and 1992 and, of these, 27 000 to 45 000 are still living (Schabas 1998).

Although it seems that parenteral contact is the most efficient means of hepatitis C transmission, this alone does not explain all infections. Further work has been done to investigate other possible modes of transmission, including perinatal and sexual transmission and non-sexual household contact with a hepatitis C–infected person (MacDonald et al. 1996). The risk of mother-to-child transmission appears to be approximately 6 per cent if the mother is viraemic (Dore et al. 1997), but the risk of transmission through other possible non-parenteral modes is less well defined.

4.2.3 Long-term outcomes

Long-term outcomes of hepatitis C infection are dependent on the proportion of cases that progress to chronic infection and, among these, the rate of progression to advanced liver disease.

In France approximately 80 per cent of hepatitis C–positive people studied had viraemia detectable by hepatitis C RNA testing and therefore remained chronically infected (Vingoe et al. 1997).

In the United States 40 to 60 per cent of chronic liver disease has been attributed to hepatitis C—about 8000 to 12 000 deaths are attributed to the virus each year (Alter 1998). In a study in Ho Chi Minh City in Vietnam 23 per cent of patients being treated for liver disease tested positive for hepatitis C antibodies (Kakumu et al. 1998).

In the United States the Centers for Disease Control and Prevention is initiating surveillance for the long-term outcomes of hepatitis C infection, such as chronic liver disease, to gain a better understanding of the natural history of hepatitis C and the risk factors for progression. The project will also facilitate evaluation of the effectiveness of treatments.

In the United Kingdom a national register of hepatitis C cases with known dates of infection is being established by the Public Health Laboratory (*Communicable Disease Report Weekly* 1998, vol. 20, no. 18) to facilitate study of the natural history of hepatitis C–related disease. The register will include people infected through transfusion of blood or blood products whose dates of infection can be identified and other people with documented dates of seroconversion.

4.3 National responses to hepatitis C

The results of the European Survey on Hepatitis C show marked variation in the level of importance different countries assign to hepatitis C as a public health concern (Nalpas et al. 1996). It was found that hepatitis C is not regarded as an important public health concern in most of Europe: nine of the 15 countries in the European Community described it as of moderate importance: it was described as a major problem in France, Italy, Denmark and the Netherlands and as a minor problem in Ireland and the United Kingdom.

National responses to hepatitis C are currently being developed and implemented in a number of countries. The US Centers for Disease Control and Prevention is finalising

guidelines for national policy in its document *A Prevention and Control Plan for Hepatitis C Virus Infection* (CDC 1998). In 1995 Health Canada published 'Prevention and Control of Hepatitis C: guidelines and recommendations' in a supplement to the *Canada Communicable Disease Report*. Health Canada plans to update the guidelines in response to a consensus meeting in October 1998.

4.3.1 Surveillance

Europe

Vingoe et al. (1997) found substantial differences in the surveillance systems in the countries they evaluated—France, Germany, Ireland, the Netherlands and the United Kingdom—for the European Monitoring Centre for Drugs and Drug Addiction. In Germany notification of all hepatitis C diagnoses is mandatory but this is not enforced; under-reporting is estimated at around 80 per cent. In France there is a voluntary surveillance system involving a 1 per cent representative sample of doctors. In Ireland there is no national surveillance for hepatitis C, although the Department of Health plans to establish a Communicable Disease Surveillance Centre to monitor hepatitis C. In the Netherlands, hepatitis C prevalence has mainly been assessed through surveys of injecting drug users.

Surveillance in the United Kingdom is undertaken through clinicians and is based on symptomatic presentation with non-A, non-B hepatitis, which occurs in, at most, 30 per cent of hepatitis C infections. There is a separate notification system for positive hepatitis C serology through public health laboratories in England and Wales (Vingoe et al. 1997). The Public Health Laboratory Network at the Communicable Disease Surveillance Centre undertook enhanced surveillance with a view to extending the laboratory reporting system (Ramsay et al. 1998): it was found that risk factors are requested by public health laboratories but that not all laboratories participate in the notification system and there is substantial variation in the completeness of information provided.

Vingoe et al. (1997) concluded that, on the whole, data on risk behaviours are very limited. Data on seroprevalence in population groups at higher risk are not routinely collected in most countries and risk behaviours are poorly linked to prevalence data in the general population. Further, most countries have been unable to distinguish between prevalent and incident cases, which means information on current transmission rates is unavailable.

North America

In the United States the Centers for Disease Control and Prevention's Notifiable Diseases Surveillance System includes notifications of hepatitis C. A variety of surveillance methodologies are used to gauge the prevalence of the disease.

The Sentinel Counties Study of Acute Viral Hepatitis has been running in the United States for 20 years and has followed changing patterns in the incidence of hepatitis C. The Study recorded substantial drops in transfusion-induced cases after the introduction of measures to exclude potentially infected donors in the mid-1980s.

Among the main risk factors for hepatitis C infection identified by the Study are sexual contact and injecting drug use. The Study has also reported an 80 per cent decline in incident infections since 1989. With such a large decline, the Centers for Disease Control and Prevention has found that the Study's ability to detect overall trends in incidence is reduced and recommends that it be expanded in order to continue to provide reliable and accurate information (CDC 1998).

Serological surveys are also conducted periodically at national, state and local levels to monitor the prevalence of hepatitis C infection in the United States. As noted, the third National Health and Nutrition Examination Survey was conducted by the Centers for Disease Control and Prevention between 1988 and 1994. This Survey provided reliable data on the prevalence of hepatitis C infection in the United States from a representative sample of the population.

In all but one health jurisdiction in Canada the Laboratory Centre for Disease Control must be notified of hepatitis C (Health Canada 1995, Tepper 1998). In its 1995 guidelines, Health Canada advised that surveillance figures do not give a true indication of the extent of hepatitis C prevalence and incidence. It claimed that surveillance could be improved if notifications were provided by all laboratories in the country and if further surveillance data were collected through other sources such as doctors.

4.3.2 Prevention and education

Europe

Policies designed to prevent HIV and hepatitis B transmission through eliminating the sharing of injecting equipment are also considered relevant to the prevention of hepatitis C transmission. The Consensus Conference on Hepatitis C in France recommended that hepatitis C prevention among injecting drug users be formally incorporated in HIV prevention, including the provision of anonymous screening sites and the availability of harm-reduction measures such as needle exchanges (Vingoe et al. 1997). Almost all European Community countries now have needle exchange programs and syringes are available without a medical prescription in all but three countries (Nalpas et al. 1996). Other preventive policies relating to domestic and sexual transmission vary considerably between countries.

North America

In both the United States and Canada the identification and diagnosis of people with hepatitis C infection are regarded as central to the prevention of further transmission and to disease monitoring and treatment. Harm-reduction approaches such as needle exchanges are not encompassed in the policies of either the Centers for Disease Control and Prevention or Health Canada. Needle exchanges have, however, been instituted in Canada in response to the HIV epidemic (Gold et al. 1997; Strathdee et al. 1997). In the United States, needle exchanges have been introduced in some states and associated reductions in the transmission of hepatitis C have been reported (Hagan et al. 1995). Nevertheless, concern that harm-reduction measures encourage injecting

drug use has prevented the introduction of needle exchanges in most jurisdictions (Lurie & Drucker 1997).

The Centers for Disease Control and Prevention has identified groups at risk of hepatitis C and recommends counselling and health education programs to reduce risk-taking behaviours and to educate people who are infected about avoiding further transmission. People considered most at risk are those who ever inject drugs. Also defined as being at risk are people who received donated blood or tissue before July 1992, people who received clotting factor before 1987, people who have ever been on haemodialysis, people who report multiple sexual partners or who have had sex with a hepatitis C–infected partner, and the children of hepatitis C–infected mothers.

4.3.3 Testing

Europe

European Community member nations began screening donated blood for hepatitis C antibodies between 1989 and 1993 (Nalpas et al. 1996). It is assumed that all countries screen organs donated for transplantation, although this is not always specified in official policies. In some countries it is mandatory to screen donated semen, but in others there are no official policies. In France hepatitis C testing is recommended for pregnant women, for family members of people with hepatitis C, for people with a history of blood transfusion, injecting drug use or invasive surgery or procedures, and for people whose liver function test is abnormal (Vingoe et al. 1997).

A 1998 report released by the South and West National Health Service Region in the United Kingdom examined a proposal to offer screening and treatment for hepatitis C to injecting drug users and people attending sexually transmissible disease clinics. The report was inconclusive but recommended more study into the costs and health benefits of such a program.

North America

Identification and diagnosis of people at risk of hepatitis C has been an important component of the US response. The Centers for Disease Control and Prevention recommends screening of people in groups identified as high risk (see Section 4.3.2). On the basis of current transmission data, the Centers does not recommend routine screening of pregnant women (unless they are otherwise at risk) and does not advise against pregnancy or breast-feeding in women with hepatitis C infection. Screening of non-sexual household contacts is also not recommended.

In Canada testing is recommended for people with any history of injecting drug use, people who were transfused with blood or received blood products before May 1992, people such as health care workers who report a needlestick injury with material from a known hepatitis C–infected source, recipients of organ or tissue transplants, the children of hepatitis C–infected mothers, and people with other liver abnormalities.

4.3.4 Treatment and care

Europe

Interferon is commercially available in all European Community countries. Nine of the 15 countries also have commercially available ribavirin. Designated reference centres exist in France, Ireland, Luxembourg and the Netherlands. All countries have criteria for the initiation of interferon therapy, although the criteria vary greatly.

North America

The Centers for Disease Control and Prevention has recommended that all people identified with hepatitis C infection be evaluated for the presence of chronic liver disease and that those with chronic liver disease be managed by an appropriate specialist. Interferon therapy is recommended for people who are found to be at risk of progressing to cirrhosis.

In Canada a consensus statement by the Canadian Association for Study of the Liver recommended interferon therapy in cases of acute hepatitis C infection (Sherman 1997). It is assumed that most cases of acute infection are detected in health care workers and transfusion recipients. In the case of needlestick injuries to health care workers, polymerase chain reaction–based assays are recommended to make a prompt diagnosis. In the case of patients with chronic hepatitis C, the report suggests they be selected for treatment on the basis of elevated ALT (alanine aminotransferase) levels. Patients who have progressed to cirrhosis do not respond to interferon therapy as well as those who have not, and recommendations for treatment in these cases should be based on the clinician's judgment of the severity of disease.

4.4 Conclusion

Surveillance of hepatitis C prevalence and incidence in global populations presents a number of important difficulties, principal among them the fact that hepatitis C infection is largely under-reported in routine notification systems and multi-faceted approaches are needed to detect cases and determine the extent of infection at a population level.

Despite limitations, global surveillance data and published studies in specific populations have established that a large number of people are chronically infected with hepatitis C globally and infection continues to be transmitted. The most efficient means of transmission is parenteral. Since the screening of donated blood has been introduced, the primary risk factor for hepatitis C infection in industrialised countries is injecting drug use. Studies of injecting drug users consistently demonstrate high rates of hepatitis C infection and a high incidence of new infections.

A number of countries are working to enhance their surveillance efforts—using routine notification, screening and sentinel surveillance in higher risk populations—in order to provide more reliable information about the epidemiology of hepatitis C.

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RESCINDED

5 The personal and social impact of a hepatitis C diagnosis

This chapter is the work of Mr Justin Rowe, who is the past president of the Hepatitis C Council of Victoria and was the Victorian Hepatitis C Educator and Counsellor from 1995 to 1998. Its purpose is to provide an insight into the psychological impact on an individual who receives a hepatitis C diagnosis. The discussion is not meant to be exhaustive; rather, it offers 'snapshots', to increase our understanding of what it may be like to live with hepatitis C. Unless otherwise sourced, quotes represent a synthesis of Justin's experience as a counsellor.

5.1 What is known about hepatitis C and what an individual diagnosed with hepatitis C wants to know

Most people newly diagnosed with hepatitis C need health professionals to give them the basic facts about the virus—what is the hepatitis C virus? how is it transmitted? what are the consequences of infection? and so on.

Each 'fact' revealed by a health professional can give rise to more questions as the patient tries to apply the information to himself or herself. Table 5.1 summarises some of the facts about hepatitis C and common responses from patients.

The questions a newly diagnosed person asks can hold the key to finding a way to help them integrate hepatitis C (and all that goes with it) into their life. Their anxiety about the consequences of hepatitis C infection—and their confidence in receiving high-quality health care—can be increased or decreased by the way a health professional answers these questions.

When I've got the flu, is it the flu, or hep C? Is it withdrawal or hep C? Though the truth is, I've never felt like this withdrawing before. I can only be sure when I get the liver pain.

—Alice, 39, Melbourne
(Burrows & Bassett 1996, p. 19)

5.2 The time of diagnosis

It is important to take the client back to their time of diagnosis since this is the beginning of their story with hepatitis C. How and why were they tested? Who requested the test? Was pre-test counselling given? Was accurate information given before the test? What did the client do once they were diagnosed? Who did they go to for initial support—a friend? a partner? Did they change any aspects of their behaviour?

Table 5.1 Facts about hepatitis C and common responses from patients

Clinicians' facts	Patients' questions
There are many strains of the virus.	What strains do I have?
There are no clinical predictors for disease outcome.	What will happen to me? Will I die?
A small number of people will clear the virus.	How do I know if I will be one of those people?
There is no effective cure.	Will I have this forever?
There is no vaccine.	How can I protect my partner or children?
A long time can elapse between acquisition and diagnosis.	How many people could I have infected?
The virus has an insidious and often asymptomatic effect on the liver.	Why do I feel fine even though the biopsy showed cirrhosis?
Only a small fraction of people suffer acute hepatitis C.	How could I have not known I have hepatitis C?
Hepatitis C is often confused with other forms of hepatitis.	I had hepatitis A when I was a kid so could I have had hepatitis C then? Does that mean I will die sooner?
Symptoms and the course of disease vary for each sufferer.	Why do I feel really tired all the time but my friend who got hepatitis C at the same time drinks heaps and is OK?
The clinician explains the clinical meaning of antibody and viral titre laboratory tests.	What is the difference? How can I have a negative PCR result yet be positive for hepatitis C antibody?
The clinician explains the functions of the liver.	Why do I feel fine even though my ALT has increased? What does it mean?

Pre-test counselling is designed to reduce the impact of a positive diagnosis. But very few people receive such counselling; indeed, many people are not told they are being tested for hepatitis C. Such a situation often leads to a negative dynamic between client and health professional. Clients can transfer their feelings of anger, disbelief and mistrust to the medical system itself and, more particularly, the practitioner who has delivered the hepatitis C diagnosis. These feelings need to be dealt with—not diffused or deflected—before moving forward through the client's story.

In addition to the frequent lack of counselling and information, people who have injected drugs, or who are assumed to have become infected with hepatitis C in this way, are often treated with contempt or hostility by doctors and other health care workers.

Discrimination! The anaesthetist when I was having an operation said, 'You've got to pay for your sins.' This was very offensive to me. I told him off. When I was on interferon the doctor taking the tests said, 'You people!' in a terrible way. I walked out. I work with doctors and I hear them saying, 'Druggies', 'Don't touch him, he's hep C', 'Don't worry about them, they're just druggies'. These are your professionals. I think, 'Shit, I hope they don't find out about me.' If doctors think like that, just imagine how the general public thinks.

—Joy, 38, Perth
(Burrows & Bassett 1996, p. 34)

People tested for hepatitis C are also often subject to a lack of confidentiality, and in custodial situations their health can be further compromised by deficiencies in treatment and measures designed to prevent transmission.

In prison ... in 1989, 25 of us were tested for hep C and we were all positive. We thought we'd got it from each other. No one was really scared. We got no info, there was no confidentiality. We were called in in a group and given our results. I didn't feel too bad because everyone had it. There are a lot of people who have it and don't know.

—Steve, 30, rural Tasmania
(Burrows & Bassett 1996, p. 13)

5.3 The time that can elapse between acquiring hepatitis C and being diagnosed

A person's psychological response to finding out that they have been exposed to hepatitis C does not seem to be affected by whether the exposure was recent or took place long ago. The longer the time lapse, however, the more life history needs to be explored and the more complex is the web of relationships. The fact that hepatitis C lies undetected can result in a person believing that this is a silent and secret disease: this may bring to the surface other psychological traumas that the person has been silent about for a long time; examples are childhood abuse and family violence, whether emotional, physical or sexual, and other experiences of isolation, whether geographic, economic, emotional or cultural. Dysfunctional and isolating behaviours may be stimulated by a diagnosis of hepatitis C; for instance, phobic disorder, depression, panic attacks or obsessive-compulsive disorder. Alternatively, these behaviours may become evident in a partner or other family member once they find out about someone's diagnosis with hepatitis C.

5.4 Telling others

The isolation many people feel upon being diagnosed with hepatitis C can be counteracted if they tell others of the diagnosis—that is, if the secret is turned into an open truth. Encouraging the patient to tell others, particularly friends and family, can be an important way of helping the patient come to terms with their illness. The patient should decide who they want to tell and when and where, and they should be helped to plan and rehearse the telling.

A 28-year-old male rehearsed his 'telling strategy' with one long-term male friend and a female cousin both isolated by distance from the client's current personal social network. This enabled the client to measure and assess his response to their responses. Thus he fine-tuned his telling strategy and this reduced his anxiety sufficiently for him to tell his spouse—a far more positive event than he had imagined.

5.5 The main routes of transmission

Tattooing, body piercing, injecting drug use, occupational exposure (particularly needlestick injuries) all have one element in common—a needle and a person. Yet the

social contexts in which people are involved in these situations and the variety of locations in which the situations occur suggest that personal interpretations are different for each person. It can be said that there is a predominant social understanding of injecting drug use that has a very real, and experienced, negative effect on the social interpretation of hepatitis C for people living with the virus. Case studies illustrate this.

5.5.1 Injecting drug use

Again and again, people use the same words and phrases to describe the impact of injecting drug use on their lives. These words and phrases are often reflective of the negative social perceptions and stereotypes connected with injecting drug use, which many people who have injected drugs, or still do, seem to adopt.

The ex-injecting drug user

People who used to inject drugs but no longer do so often find they must revisit their injecting life as they try to incorporate a hepatitis C diagnosis in their present lives. The personal reasons for drug use (including problems that may have never been resolved), the drug of choice, the social group most strongly linked to the drug use, the lifestyle and associations ... the whole 'history' of 'that life' is revisited. For some, this presents little difficulty; for others, it can pose myriad problems, an extreme response being a return to drug use.

A 35-year-old mother of two (4- and 6-year-olds) who had a period of injecting drug use for two years over 15 years ago.

Recently diagnosed and told 'not to worry everything will be fine'. Wants to get her children tested but does not want to inform her partner who knows 'nothing of that "junk" history and would probably leave her if he knew the "truth"'. On further exploration the personal meaning of 'junk' history was embodied in the words 'filthy, grotty, slut'. The 'truth' was a two-year period of this woman's life, which included a friend's death by overdose, a fatal car accident, a suicide attempt and an overdose. This woman had never had counselling and went 'cold turkey at an aunt's holiday house with a friend (now deceased)'. For her, hepatitis C was 'the punishment' and her aim was to reduce the impact and extent of 'the punishment'. She viewed her partner as 'straight, conservative and would not cope with her history' ... his response would be to 'never trust her again'.

The current injecting drug user

Some people who inject drugs and become infected with hepatitis C may accommodate the disease by seeing it as one of a number of pressing problems: finding housing and work, getting drugs, maintaining relationships, and so on. Others may simply face the problems that also confront people infected through other means—except for the implications of their illicit drug use and the attendant discrimination.

Living with the threat of arrest, death from overdose and discriminatory treatment by health care workers can make hepatitis C a low priority in some injecting drug users' lives.

In addition, many people who inject drugs have already been warned about two other blood-borne viruses that are transmitted by sharing injecting equipment but may not have had an impact on their lives: hepatitis B and HIV. This can result in a cavalier attitude to the consequences of hepatitis C infection.

The knowledge that many of their peers are hepatitis C positive, without concomitant knowledge that exposure does not prevent re-infection with other strains of the virus, can produce a fatalism about infection. These factors, together with predetermined attitudes on both sides of therapeutic relationships, can present formidable obstacles to effective education, treatment and support for hepatitis C-positive people who inject.

Among other problems for hepatitis C-positive injecting drug users are how the diagnosis will affect their relationship with the group from whom they obtain support; how it will affect their sense of separation from society and the distinction they make between those who use drugs and those who don't; how it will affect the risk of overdosing; and how it will affect their thinking about detoxification or attempting to repeat detox at home or elsewhere.

A 28-year-old male and a 24-year-old female, living together for four years.

Both are hepatitis C positive, injecting and sharing needles and syringes for over a year and using heroin twice a week. Both employed and 'struggling' to save for deposit on a house. Sought counselling because 'she wants to have a child and is worried about transmission'. After a long talk the woman stated she believed getting pregnant would be the only motivator for 'both of them to get clean but she doesn't want the kid to have hep C'. Concerned about effect of detox whilst pregnant and how to go about it at home. Neither of them have any support, as both families are interstate.

5.5.2 Tattooing and body piercing

Social and personal meanings of tattooing and body piercing vary in keeping with cultural norms. The personal meaning of a tattoo is often a matter of peer association, intimate partnership, independence, and individuality.

A 67-year-old man diagnosed with primary liver cancer due to hepatitis C virus.

A career army officer who retired 12 years ago to work on the land with his spouse. Three live children and seven grandchildren. Had numerous tattoos from various locations. Sought counselling because he 'did not want anyone to know that he has got a drug addict's disease'. He had ceased contact with his children so as to 'reduce the risk of transmission of this filthy virus to the grandkids'.

5.5.3 Infected blood

People receive blood products for many reasons, but the following case describes some of the feelings associated with knowing you have received a blood product contaminated with hepatitis C.

A 42-year-old mother of three received a blood transfusion with the emergency birth of her youngest child (now 12 years old.)

Diagnosed as part of an employment screen two years ago. Sought counselling because she wants the child to be tested as she breast-fed, but doesn't know how to go about [the testing] without informing the child. After long discussion she states that ever since she was diagnosed her spouse shows 'less interest in her and he never wants to discuss it'. She said 'she was confused about it because the blood transfusion probably saved her life and she has three beautiful children but it has now ruined her relationship. He wants to sue but she just wants things to go back to normal—like they used to be'. For this client hepatitis C was the first 'event for the relationship to resolve that was outside the normal family life'.

5.6 Other difficulties associated with transmission

People often feel anxious about transmitting hepatitis C after they have been diagnosed. Some have said they feel 'marked', 'tainted', 'permanently scarred', 'ostracised'. Many live with misinformation, myths and the projected fears and anxieties of non-infected people (family members, friends, work mates, the media) as well as others who have the virus. Every day they move between 'remembering' that they are infected with the virus and 'forgetting' this.

Hepatitis C cannot be transmitted via household utensils such as cups or spoons; nor can it be spread via saliva, so kissing and hugging pose no risk. The virus is transmitted by direct blood-to-blood contact, sexual contact involving blood-to-blood exchange, occupational exposure and pregnancy. There is also a possibility of transmission through sharing toothbrushes, razors and nail scissors. These numerous possible points of transmission (some of which appear to carry only very low transmission risks) mean people 'remember' they have hepatitis C many times in their day-to-day lives.

Blood has many social connotations, and individuals come into contact with it in a variety of social contexts. Since the hepatitis C virus is transmitted through direct blood-to-blood contact, messages about prevention of transmission primarily deal with blood awareness and placing a barrier between the individual and blood. For some people, such messages can trigger serious anxiety.

A 27-years-old female diagnosed three years ago, with no known risk other than sharing accommodation with a possible occasional injecting drug user.

For this women the very fact of having hepatitis C meant she could not trust blood and she didn't even have to be able to see the blood. This translated into her becoming excessively vigilant about her own blood (for example, soaking her sheets in bleach for a day after menses had finished, cleaning the toilet with bleach after she used it whilst menstruating, washing all her clothes and linen separately from anyone else). She sought counselling because she had not had a partner since her previous relationship (three years ago), which ended once she told her partner she had just been diagnosed with hepatitis C and 'they must use condoms'.

The context of sexual transmission is little researched and remains mysterious to both the health care profession and the community at large. There is no absolute conclusion in relation to sexual transmission, so safe sexual practices are encouraged with new partners, as is protected vaginal and anal intercourse.

For pregnant women, the risk of transmission from mother to baby is low. At present there is no firm evidence of transmission via breast milk, although if the mother has cracked nipples it is recommended that she cease breastfeeding until the skin has healed. It has also been suggested that hepatitis C–positive women and their partners avoid unprotected vaginal intercourse during menstruation.

The 'window' period for seroconversion to hepatitis C is six months, so someone who is exposed to the virus must wait for confirmation and engage in safe sexual practices during that time. For anyone at risk of exposure it is also important to explore pregnancy, breastfeeding and protected sex. Furthermore, for a large number of people who have been exposed to hepatitis C through their work there can often be shame associated with 'the incident'. A person's ambivalence about behaviour change can increase anxiety about transmission, which in turn can affect the quality of the primary relationship.

A 26-year-old woman had a needlestick injury from a known hepatitis C–positive source.

The needle penetrated all layers of the skin but the plunger of the syringe was fully depressed before this happened. The woman and her partner had been 'trying to get pregnant for the last three years, contemplating going into IVF'. Issues around safe sex for the next six months were of major concern for it meant she would have to tell her partner, which meant they would have 'another reason to avoid pregnancy'. Personal beliefs: the needlestick was her fault and not getting pregnant was her fault; therefore her partner will leave her because she is a 'failure as a woman'.

5.7 Discrimination

Discrimination can occur in a variety of contexts. Much of the discrimination people living with hepatitis C experience is a result of beliefs, values and attitudes associated with injecting drug use (that is, user phobia).

Of course people with hepatitis C don't like being treated like junkies. Hell, drug users don't like being treated like junkies.

—injecting drug user group, South Australia
(Burrows & Bassett 1996, p. 40)

A person whose hepatitis C diagnosis becomes widely known may experience discrimination from broad social networks—friends, local businesses, sporting groups, and institutions such as schools, hospitals, health and dental clinics, and child care facilities.

Many instances of discrimination experienced by people living with hepatitis C have been reported. Examples are access to children being denied because of a parent's hepatitis C status; difficulty obtaining dental or medical care because of hepatitis C status; parents not allowing their children to play with children of hepatitis C–infected parents; discrimination based on the perception that all people with hepatitis C are drug users; and discrimination in the workplace (particularly in the hospitality industry).

At home, a person living with the virus may find their relationships change within the family unit. The family will often make changes to personal hygiene and daily living

habits to decrease the risk of household transmission. This can be very isolating for the infected person.

Infected people can also impose discriminatory behaviours on themselves. This can lead to denying themselves normal relationships and being excessively anxious and vigilant about bodily fluids and personal hygiene.

The different forms of discrimination reflect the differing effects of misinformation in the broader community, combined with general 'germ phobia', which is strongly attached to user phobia. The myths, misrepresentation and misinformation about hepatitis C are extensive.

A case study of 37 people with hepatitis C found a high proportion of subjects suffered from discrimination—46 per cent in the health care setting, 22 per cent in a domestic context, 20 per cent at work and 10 per cent in a recreational, social security, day care, funeral or prison setting (Crofts & Louie n.d.). Although none of the incidents was pursued under the various Discrimination Acts in Australia (which make discrimination on the basis of hepatitis C status illegal) the incidents were reported to have had a substantial personal effect on 83 per cent of subjects. This included an impact on personal relationships (63 per cent of the subjects), social implications (61 per cent), occupational implications (44 per cent) and financial implications (37 per cent). Crofts and Louie call for an urgent look at discrimination against people with hepatitis C.

5.8 Conclusion

It is not possible to arrive at a simple conclusion about the personal and social impact of hepatitis C. Yet it is possible to suggest that the personal impact can be reduced over time with suitable psychosocial support, including peer-based and professional counselling. The central challenge for all people infected with hepatitis C or affected by a hepatitis C diagnosis is the widespread discrimination against people who inject drugs or who are perceived to have become infected in that way.

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6 Knowledge and behaviours relating to transmission of hepatitis C

This chapter draws together work undertaken at the National Centre in HIV Social Research (Lindsay et al. 1997; Crawford et al. 1998), the Macfarlane Burnet Centre for Medical Research (Crofts et al. 1996) and the National Centre in HIV Epidemiology and Clinical Research (Macdonald et al. 1998).

6.1 Knowledge in the general community

At present there is little information about the general community's awareness of the hepatitis C virus. Two large studies, however, suggest limited or patchy knowledge. One study, conducted in 1997, involved a nationally representative survey of 3550 government-school students in years 10 and 12 (Lindsay et al. 1997); the other, conducted in 1996, involved a national telephone survey of 3039 homosexually active men (Crawford et al. 1998).

The survey of students revealed poor knowledge about the hepatitis C virus: the correct response to seven questions on hepatitis C was given by more than half the students on only one occasion (see Table 6.1). Some students wrote on their questionnaire forms that they did not know what hepatitis was and so could not answer the questions. For all the questions about transmission of hepatitis a significant proportion of students chose the 'don't know' option. Among the students who did give a positive or negative response there was little evidence of differentiation between different forms of hepatitis.

Table 6.1 Students' responses to statements about hepatitis

Statement	Response (%)			N
	True	False	Don't know	
Hepatitis C has no long-term effects on your health.	8.4	36.2	55.4	3 509
It is possible to be vaccinated against hepatitis A.	37.8	6.6	55.6	3 507
It is possible to be vaccinated against hepatitis B.	42.9	6.5	50.6	3 507
It is possible to be vaccinated against hepatitis C.	30.6	8.0	61.4	3 502
People who have injected drugs are not at risk for hepatitis C.	4.6	56.0	39.4	3 503
Hepatitis C can be transmitted by tattooing and body piercing.	36.9	9.3	53.8	3 498
Hepatitis B can be transmitted sexually.	42.9	4.8	52.3	3 504

Note: Correct responses are shown in bold type.

Source: Lindsay et al. (1997).

It is of note that only a small minority of respondents (8 per cent) knew there is no hepatitis C vaccination. Uncertainty about hepatitis was further illustrated by the data on hepatitis vaccination: a large proportion of students were unsure whether they had been vaccinated or not; almost one-third of those who claimed to have been vaccinated seemed to hold the generic belief that they had 'had their shots' by reporting they had

been vaccinated against hepatitis A, hepatitis B and hepatitis C (even though there is no hepatitis C vaccination).

The students revealed poor knowledge about the transmission of hepatitis through injecting drug use and the sharing of needles and other equipment (see Table 6.2). Just over half correctly responded that hepatitis C and hepatitis B can be transmitted through injecting; very few knew that hepatitis A cannot be transmitted in this way. Of the 3475 students who answered all three questions only 51 (1.4 per cent) answered all three correctly.

Table 6.2 Students' responses to questions about transmission through injecting drug use

Question	Response (%)			N
	Yes	No	Don't know	
Can hepatitis A be transmitted by injecting when sharing needles and other equipment?	55.1	7.0	37.9	3 502
Can hepatitis B be transmitted by injecting when sharing needles and other equipment?	57.9	5.9	36.2	3 519
Can hepatitis C be transmitted by injecting when sharing needles and other equipment?	54.6	7.2	38.2	3 514

Note: Correct responses are shown in bold type.

Source: Lindsay et al. (1997).

The students' poor knowledge about hepatitis C contrasted dramatically with their consistently high level of knowledge about the transmission of HIV.

The survey of homosexually active men revealed patchy, and by no means universal, knowledge about hepatitis C (see Table 6.3). Many of the statements elicited a high proportion of responses in the 'don't know' category. Further analysis (not shown here) of the data by respondents' age reveals that men under 30 years old were more likely than men aged 30 to 49 years to respond 'don't know' and were more likely to respond incorrectly.

6.2 Transmission of hepatitis C by injecting drug use

People who inject drugs are at risk of infection with HIV and the hepatitis B, C and Delta viruses through the sharing of contaminated injecting equipment, the sharing of blood by other means, and sexual contact. Because of the very high proportion of prison inmates who have histories of injecting drug use and tattooing and because risk behaviours continue in the prison setting, prisoners are also a group at increased risk of infection with these viruses. An important part of Australia's response to the threat of hepatitis C and HIV infection among injecting drug users has been education aimed at decreasing the sharing of injecting equipment and the provision of sterile needles and syringes and expanded drug-treatment programs.

Table 6.3 Homosexually active men's responses to statements about hepatitis

Statement	Response (%)			N
	True	False	Don't know	
Hepatitis C has no long-term effects on your health.	3.1	72.4	24.5	3 036
It is possible to be vaccinated against hepatitis A.	57.6	11.3	31.1	3 039
It is possible to be vaccinated against hepatitis B.	75.8	5.1	19.1	3 039
It is possible to be vaccinated against hepatitis C.	23.9	39.4	36.8	3 039
Hepatitis C can be transmitted by sharing razors or toothbrushes.	61.5	9.3	29.2	3 038
Hepatitis C can be transmitted by tattooing and body piercing.	66.9	5.4	27.7	3 037
Hepatitis B can be transmitted sexually.	76.7	3.3	20.0	3 039

Note: Correct responses are shown in bold type.

Source: Crawford et al. (1998).

Figures 6.1 to 6.4 summarise cross-sectional surveys of injecting drug users in New South Wales, Victoria, Western Australia and Queensland undertaken between 1985 and 1997. The figures are based on a summary of 28 quantitative research studies carried out among injecting drug users between 1985 and 1994 (Crofts et al. 1996). The National Centre in HIV Epidemiology and Clinical Research updated the Crofts study by summarising recent cross-sectional studies (Macdonald et al. 1998, Lenton & Tan-Quigley 1997, Rumbold & Fry 1997, Fry et al. 1998, Maher et al. 1998, Hando & Darke 1998). The summary of the cross-sectional surveys included all known studies that asked whether respondents had used a needle or syringe that they knew had been used by someone else in the preceding month.

As Figures 6.1 to 6.4 show, throughout the decade there has been an overall downward trend in the proportion of injecting drug users reporting use of needles and syringes after they have been used by someone else, although there is considerable variation between studies. The sources of this variation are multiple, but especially include sampling from different population groups, socio-geographically defined. The downward trend is emphasised by the high rates of re-use found in the early studies (1985 to 1988). It is difficult to detect any systematic differences in behaviour between cities.

A slightly more complex picture arises when groups of studies with larger sample sizes and similar methodologies are highlighted against the backdrop of the other cross-sectional studies. Three main groups of studies can be examined: the Victorian Injecting Drug Users Cohort (VICS); the Australian National AIDS and Injecting Drug Use Study (ANAIIDUS) and the Australian Study of HIV and Injecting Drug Use (ASHIDU); and the National Centre in HIV Epidemiology and Clinical Research (NCEHCR) survey of needle and syringe exchanges (identified as Macdonald et al. in Figures 6.1 to 6.4) (Macdonald et al. 1998).

The results of the ANAIIDUS group of studies in 1989–90 were 22.0 to 37.5 per cent of injecting drug users reporting re-use after someone else in the previous month; the figure dropped to 9 to 16 per cent in 1994 in the ASHIDU group of studies (Crofts et al. 1996, p. 8).

Figure 6.1 shows that in the VICS study—a cohort of drug users followed longitudinally between 1989 and 1995—there was a significant downwards trend in the percentage of injecting drug users who shared needles and syringes, with rates of 24–30 per cent being reported in 1995 (Crofts & Aitken 1997, p. 18).

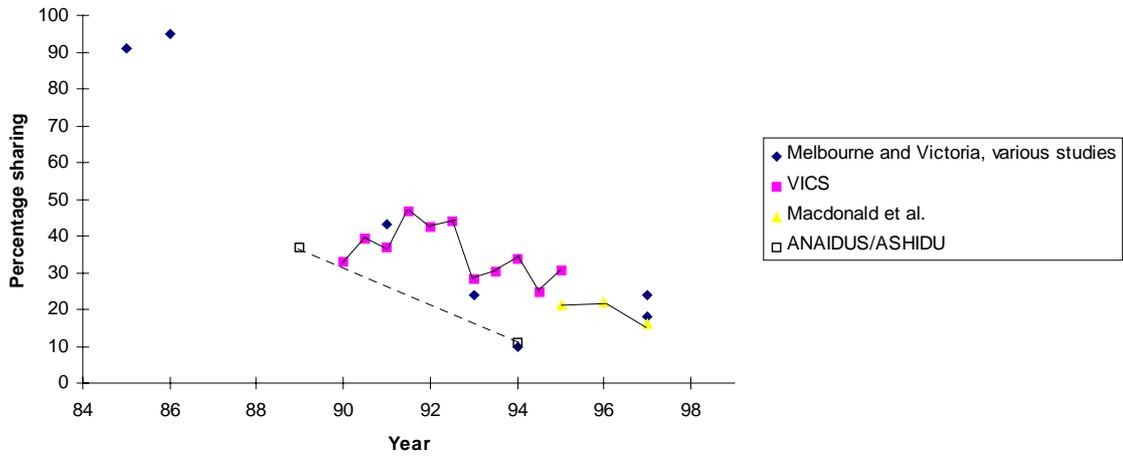
The National Centre in HIV Epidemiology and Clinical Research's national survey of injecting drug users attending needle and syringe exchanges (Macdonald et al. 1998) also suggests that a decreasing proportion of injecting drug users were engaging in behaviours that place them at risk of transmission of HIV, hepatitis B and hepatitis C. Nationally, in 1995, 31 per cent of injecting drug users had used a needle and syringe after someone else in the preceding month; in 1996 the proportion was 28 per cent and in 1997 it was 18 per cent.

The results of the Macdonald survey and other cross-sectional studies in Melbourne, Sydney and Perth confirm the general pattern of a decline in sharing. Taken together, the studies suggest that during 1996–97 between 15 and 32 per cent of injecting drug users had shared equipment in the preceding month.

The data for 1995 onwards suggest that sharing rates during the early 1990s did not decline as dramatically as suggested by the ASHIDU group of studies. They show that throughout the late 1990s up to 30 per cent of injecting drug users had shared injecting equipment during the preceding month. Further investigation is needed to understand whether other aspects of injecting behaviour have changed during the 1990s.

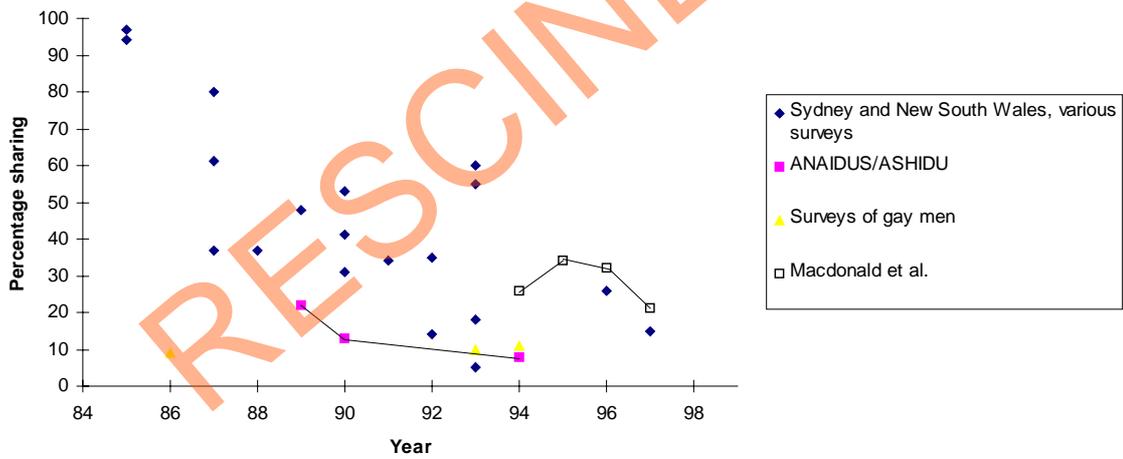
It should be noted that the number of needles and syringes distributed through free needle and syringe exchanges and bought through pharmacies increased markedly during this period: in 1994–95, 13.9 million needles and syringes were distributed; in 1995–96, 15.5 million were distributed; in 1996–97, 19 million were distributed. These figures add weight to the argument that, if behavioural change among injecting drug users is to be maintained and extended, any expansion of needle and syringe exchanges should be accompanied by additional health-promotion programs.

Figure 6.1 Percentage of injecting drug users sharing needles and syringes in preceding month, 1985 to 1998, Victoria



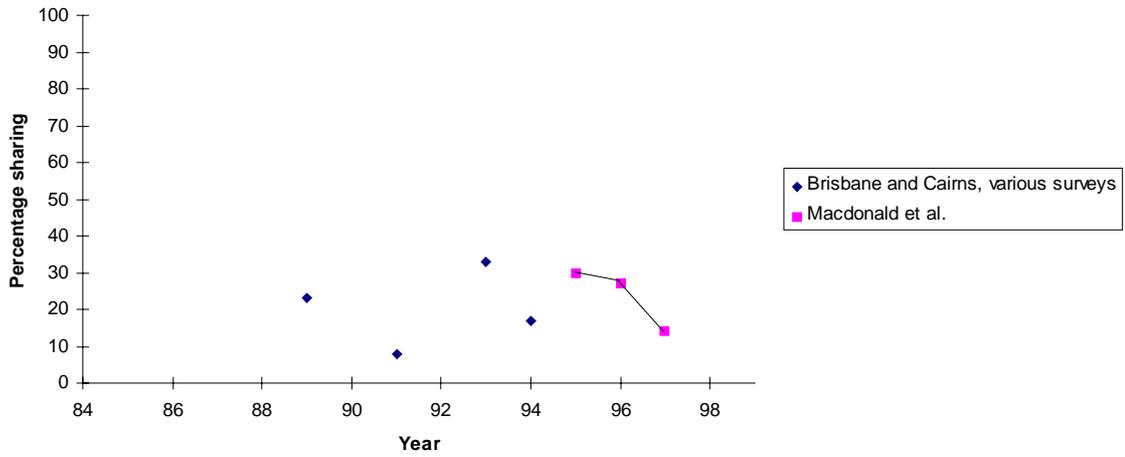
Source: Crofts et al. (1996), Crofts and Aitken (1997), Macdonald et al. (1998), Rumbold and Fry (1998).

Figure 6.2 Percentage of injecting drug users sharing needles and syringes in preceding month, 1985 to 1998, New South Wales



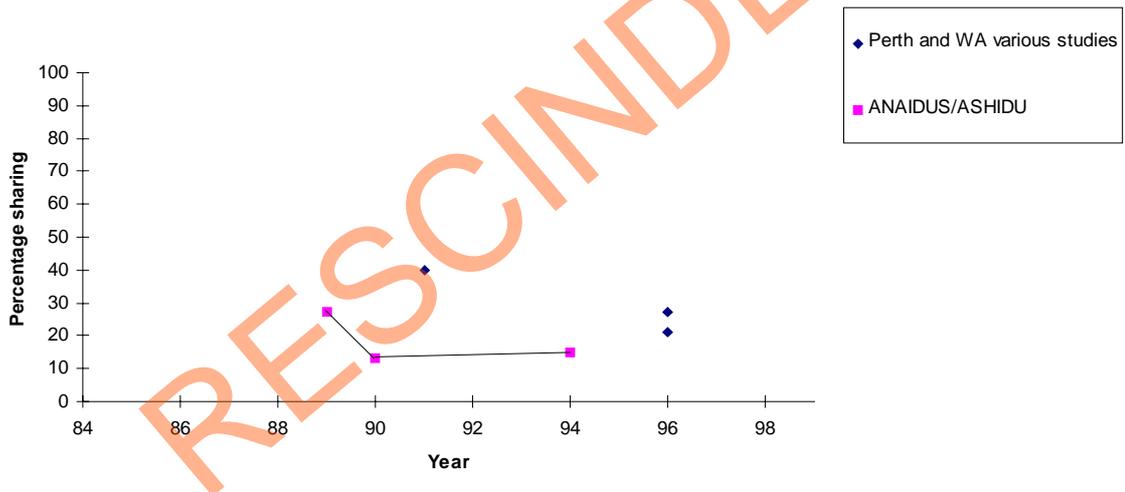
Source: Crofts et al. (1996), Hando and Dark (1998), Macdonald et al. (1998), Maher et al. (1998).

Figure 6.3 Percentage of injecting drug users sharing needles and syringes in preceding month, 1985 to 1998, Queensland



Source: Crofts et al. (1996), Macdonald et al. (1998).

Figure 6.4 Percentage of injecting drug users sharing needles and syringes in preceding month, 1985 to 1998, Western Australia



Source: Crofts et al. (1996), Lenton & Tan-Quigley(1997), Macdonald et al. (1998).

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RESCINDED

7 Economic analyses relating to hepatitis C

This chapter summarises the report entitled 'Economic Analyses for *Hepatitis C: Australia's response* by Mr Alan Shiell. The full report, describing the methodology assumptions and data sources, is available from the Commonwealth Department of Health and Aged Care website (<http://www.health.gov.au>).

Three levels of economic analysis are presented. The first is an estimate of the direct costs of hepatitis C infection. Estimates of both prevalence-based costs (direct costs incurred in the current year by people already or newly infected with the virus) and incidence-based costs (lifetime costs incurred by a cohort of people each infected with hepatitis C at the same time) are presented. Incidence-based costs are more relevant to discussions about the potential cost-effectiveness of prevention strategies. The second level of analysis is an estimate of the indirect costs (those associated with lost production) that arise from premature mortality and morbidity connected with the disease. The third level of analysis presents insights into the likely cost-effectiveness of hepatitis C education, prevention and treatment.

The final section of the chapter discusses how to use this economic analysis but notes that there are major gaps in our understanding of the economics of hepatitis C that may adversely affect our ability to determine public health priorities.

7.1 The direct costs of hepatitis C infection

The direct costs of a disease are those costs incurred directly as a result of action taken to tackle specific aspects of the disease. This includes all expenditures on research, prevention, diagnosis, treatment and palliation. Prevalence-based estimates of disease costs are based on only those expenditures incurred in the base period, usually a specified year; future costs are not considered. The result provides some indication of the total cost burden of a disease and its distribution at a particular time.

To date there have been no published estimates of the prevalence costs of hepatitis C in Australia or elsewhere. The estimates presented here draw on a number of sources in order to paint a general picture of the costs associated with infection with the virus. Known expenditures of Commonwealth and State and Territory health agencies are documented and different methods of estimating treatment costs are described. Known expenditures are those for which it is possible to identify a hepatitis C-specific component. Cost estimates are incomplete.

7.1.1 Prevalence-based costs

Table 7.1 shows estimates of prevalence-based treatment costs for hepatitis C in Australia. The estimate of the total cost of treatment during 1996–97 has been derived by multiplying an estimate of the number of people in each clinically important stage of the disease and in receipt of treatment by the cost of treating that stage and summing the result across disease stages. The estimate of the number of people in each stage of the disease was taken from the work of the Hepatitis C Virus Projections Working

Group (1998). The Group identified four disease states: continuing chronic infection without evidence of cirrhosis; continuing chronic infection with signs of cirrhosis; liver failure; and liver cancer. To derive treatment-episode costs, clinical judgment was used to specify treatment protocols for each of the clinically important stages of the disease. The protocols were costed using the Medicare Benefits Schedule for medical services and diagnostic-related group costs for hospital admissions.

Table 7.1 shows the estimated total cost of treatment given the projected numbers of people at each stage of the disease and the assumed proportions of people who are in receipt of treatment—not all people know they have hepatitis C and not all people who have hepatitis C seek treatment. Table 7.1 assumes that 33 per cent of people living with hepatitis C seek care.

Table 7.1 Estimated prevalence-based treatment costs for hepatitis C in Australia, by stage of disease, 1996–97

Stage of disease	Cost per patient per year (\$)	Number of patients	Number (and percentage) of patients receiving care	Total costs
Diagnosis	343	10 500	10 500 (100)	3 603 075
Chronic hepatitis C	Year 1 359 Year 2 173	14 4000	34 200 (30)	15 493 680
Cirrhosis ^a	2 823	8 500	6 800 (80)	19 194 894
Terminal liver failure ^b	30 000	300	300 (100)	9 000 000
Liver cancer ^b	30 000	80	80 (100)	2 400 000
Total		163 380	60 880 (37)	49 691 649
Total (excl. diagnosis)		152 800	50 380 (33)	46 088 574

a. Weighted cost per case includes both compensated and uncompensated cirrhosis.

b. Costs incurred in last year of life only.

Source: Shiell (1998).

On the basis of the assumptions used, the estimated total cost of diagnosis and management of hepatitis C infection in 1996–97 was nearly \$50 million. For clinical management alone, the cost was \$46 million, which is equivalent to an average cost of \$915 per year per person receiving treatment, or \$300 per year per person exposed to the disease. If the cost estimates are based instead on the assumption that 50 per cent of people exposed to the disease seek medical attention, the total cost increases to \$60 million. Much of this expenditure falls on the Medicare Benefits Schedule, although between \$14 million and \$25 million is related to hospital admission if all care in the last year of life is provided in hospital.

In addition to estimates of prevalence-based treatment costs, Table 7.2 shows the following estimated costs for 1996–97:

- Commonwealth costs for epidemiology and surveillance;
- the cost of screening blood donations;
- spending by State and Territory health agencies on needle and syringe exchanges and peer education in relation to injecting drug use;

- Commonwealth spending on education and prevention;
- pathology testing for hepatitis C funded through the Medicare Benefits Schedule;
- Commonwealth expenditure on hepatitis C-specific research and evaluation;
- interferon treatment costs.

Table 7.2 Estimated cost of hepatitis C infection, by expenditure category, 1996–97

Expenditure category	Cost (\$)
Commonwealth epidemiology and surveillance	170 894
Blood donation screening	6 250 000
Prevention	
State and Territory needle and syringe exchanges and user groups	14 951 386
Commonwealth education campaigns	1 200 000
Diagnosis	
Medical services related to diagnosis	1 162 875
Medicare Benefits Schedule pathology services	2 985 631
Treatment	
Chronic disease and sequelae	46 088 574
Interferon	2 015 342
Commonwealth research and evaluation	173 195
Total	74 997 897

On balance, the estimates in Table 7.2 understate the total costs associated with hepatitis C because a number of other relevant expenditure categories—such as government administration costs, spending to support public health activities for a number of diseases in the same setting or for certain priority groups, the personal costs borne by people living with hepatitis C (including spending on complementary therapies), and State reference laboratory costs—are not included. It is difficult to isolate the hepatitis C component of some programs, especially programs aimed at preventing the spread of blood-borne viruses more generally. The estimates also understate the surveillance, education and prevention, and support activities funded by State and Territory health and custodial agencies.

These exclusions aside, the estimated prevalence cost of hepatitis C infection in 1996–97 was \$75 million, of which 30 per cent was spent on preventing the spread of infection.

7.1.2 Incidence-based costs

Incidence-based costs are more difficult to estimate than prevalence-based costs since they require projections of disease progression in a cohort of newly infected people. But incidence-based costs are more useful since in the case of hepatitis C they describe the potential savings that could be realised from an effective prevention program. If the costs of preventing an incident case of hepatitis C virus are lower than the costs of

treating that case then, providing there is no harm associated with the prevention strategy, prevention is obviously cost-effective.

Published incidence costs

There is one other published estimate of the incidence-based costs of hepatitis C infection. Brown and Crofts (1998) report the costs of the virus in successive cohorts of 1000 injecting drug users. The results suggest direct treatment costs of \$14.32 million for each cohort and \$0.5 billion over the entire period as successive cohorts add to the prevalence pool. With an estimated annual incidence of 10 000 new infections among injecting drug users, Brown and Crofts suggest that total health care spending on hepatitis C-related disease will reach \$4 billion in 60 years.

It should be noted that Brown and Crofts reported costs in terms of constant 1994 prices to remove the effects of price inflation but did not discount the costs to take into account the time at which they were incurred. Conventional practice is to discount costs incurred in the future (that is, reduce their real value relative to costs incurred today). Over 60 years, discounting at 5 per cent means that a cost of \$14 million spread over that period would be equivalent to an upfront cost today of \$7 million.

Estimates of incidence-based direct costs

The estimates of the incidence-based costs of hepatitis C presented here are based on projections by the Hepatitis C Virus Projections Working Group. Costs are based on a cohort of 1000 people newly infected with hepatitis C and the natural history of the disease follows the assumptions used by the Working Group. Thirty per cent of people with chronic infection, 80 per cent of those with cirrhosis, and 100 per cent of those with more severe long-term sequelae are assumed to seek medical attention. Different assumptions about the average time before the disease becomes manifest, and therefore when people seek care, are also factored into the analysis. Treatment costs for each of the disease states are the same as those used to estimate the prevalence-based costs. This method overstates costs at the beginning and end of the evaluation period and understates costs towards the middle of the period. All costs are projected over 50 years and discounted at 5 per cent; for comparison, undiscounted costs are also reported.

On the basis of these assumptions, the undiscounted cost of treating hepatitis C in a cohort of 1000 newly infected people amounts to nearly \$13 million over 50 years. The discounted cost (discounted at 5 per cent) is \$6.0 million. There are several important differences between this model and the one used by Brown and Crofts (1998). If the Brown and Crofts assumptions are used the (undiscounted) present value of the cost in the cohort of 1000 newly infected people amounts to \$16.2 million. The discounted present value of the incident cost, under this assumption, is \$7.8 million. Given price differences between 1994 and 1996, the results of this evaluation are remarkably similar to those obtained by Brown and Crofts, despite the differences in method. This suggests that the estimate of costs is fairly robust with respect to changes in the underlying assumptions.

The undiscounted lifetime average cost per case of hepatitis C of \$13 000 may appear to be on the low side. The average hides a wide variation in individual costs. On the

basis of the estimates of disease progression used here, for every 1000 people infected 250 will clear the infection within six months and require no health care. A further 642 will suffer chronic infection but will have no substantial long-term health sequelae and so have no need for expensive health care. The remaining 108 people will develop long-term complications: 74 per cent will develop cirrhosis, 18 per cent will develop advanced liver failure, and 8 per cent will develop liver cancer. Each of these people will have extensive health care needs but, even then, the mortality associated with the most severe states limits total expenditures.

The incidence-based cost of \$13 million per 1000 newly infected people over 50 years is based on current treatment protocols and probably underestimates the future costs associated with hepatitis C infection. The current model underestimates costs associated with increased rates of liver transplantation, increased use of interferon and other expensive drugs, and adoption of polymerase chain reaction testing to monitor treatment effectiveness. Countering this, however, one might expect to see some reduction in the price of drugs and the costs of expensive procedures as experience with their use is gained.

7.2 The indirect costs of hepatitis C infection

The indirect costs of hepatitis C infection relate to the loss of production that results from premature mortality, absenteeism caused by ill-health, reduced performance at work because of ill-health, movement to a less demanding job to reduce stress, and time taken off work by infected people or their carers to attend hospital or other medical services.

In practice, it is usually possible only to estimate indirect costs that arise because of premature mortality and treatment: it is difficult to track down changes in employment, absenteeism or performance at work. Such effects may be considerable, though, and their omission leads to a significant underestimate of the social and personal burden of hepatitis C infection.

The method used to estimate indirect costs takes into account days lost because of treatment and premature mortality, changes in employment participation calculated by deriving high and low estimates of indirect costs (using the employment participation rates of the injecting drug user population and the general population respectively), and lost productivity.

On the basis of the assumptions, the indirect cost of hepatitis C-related disease in 1996–97 was \$32.5 million, with best and worst estimates of \$20.8 million and \$52 million. The indirect cost associated with a cohort of 1000 newly infected people would amount to \$33.6 million over 50 years without discounting. The present value of this cost using a 5 per cent discount rate is \$17.5 million.

The estimates of indirect costs understate the loss of productivity to the extent that illness-related absenteeism not associated with health care and all non-market activity, such as housekeeping, have been excluded. Equally, however, there is in the economic literature debate about whether the methods used here overstate indirect costs since they assume that people who leave the workforce because of ill-health are not

replaced. With the levels of unemployment currently applying in Australia, this is likely to occur only where the individual concerned possesses rare skills.

7.3 The cost-effectiveness of hepatitis C education, prevention and treatment

7.3.1 Education and prevention

Efforts to prevent the transmission of hepatitis C concentrate mainly on the development of education programs targeting high-risk populations and specific measures such as the needle and syringe exchange programs. Interventions work in tandem and are most likely to have synergistic effects. Information and education campaigns, for example, will not only have a direct effect on knowledge and understanding (and thus, one hopes, behaviour) but may also help to create a context in which the effectiveness of specific interventions is enhanced. In these circumstances, it is difficult to isolate the separate (or marginal) contributions of each element of the intervention program and care must be taken to avoid attributing either too much or too little of the impact of the program to any single element. These difficulties may, in part, explain why to date there has been no published evaluation of the cost-effectiveness of measures to prevent the spread of hepatitis C.

The needle and syringe exchange program has, however, been evaluated in the context of HIV/AIDS. The program's cost-effectiveness was assessed as part of a larger economic evaluation of the HIV/AIDS Strategy 1993–94 to 1995–96. Hurley and Butler (1996) examined the program's effectiveness in reducing the rate of increase in HIV seroconversion and translated this into an expected number of lives saved and life-years gained. The costs of the program were reported and compared with the lifetime costs of treating HIV/AIDS (that is, the incidence-based costs of HIV/AIDS). Even under the most pessimistic assumptions, the program was found to be highly cost-effective, saving lives and money. Savings in treatment costs as a result of preventing cases of HIV/AIDS were more than enough to pay for the costs of the program.

Given this, any impact the needle and syringe exchange program might have on the incidence of hepatitis C comes as a 'free good'. When one factors in the benefits of preventing other blood-borne disorders such as hepatitis B and hepatitis C (benefits that come at no additional cost), the program's cost-effectiveness appears even more convincing.

Evidence suggests that needle and syringe exchanges are associated with lower rates of hepatitis C transmission in both the United States (Hagan et al. 1995) and Australia (Crofts et al. 1997). Crofts and colleagues documented a (non-significant) fall in the incidence of hepatitis C associated with a reduction in reported rates of needle sharing, from 16.6 cases per 100 person-years in 1990 to 8.1 per 100 person-years in 1995. The authors are careful not to attribute this to any formal intervention.

Although its reasons are not documented, the Hepatitis C Virus Projections Working Group (1998) did factor in a reduction in the incidence of hepatitis C among injecting

drug users, from 18 per 100 person-years in 1985 to 13 per 100 person-years in 1989. This is more modest than the reduction in incidence observed by Crofts et al. and predates it, although it is coincident with the introduction of needle and syringe exchanges in mainland Australia.

If this line of argument is extended, such a reduction means that there have been 2000 fewer people exposed to hepatitis C each year in Australia. This implies cost savings with a discounted present value of \$12 million a year.

Strictly, it is not possible to deduce from this the cost-effectiveness of expanded investment in the needle and syringe exchange program since nothing is known about the marginal effectiveness of such investment. But the magnitude of the effects just documented is such that it is highly unlikely that investment in the program has reached the point of negligible marginal return.

7.3.2 Treatment

The protracted nature of hepatitis C infection makes it difficult to evaluate the cost-effectiveness of treatment in the context of a randomised trial. The time frame required to capture the long-term effectiveness of treatment precludes the use of prospective trials. Instead, decision-analytic techniques have been used to provide some indication of the likely cost-effectiveness of treatment.

The only effective treatment currently available is with interferon, although trials of the use of Chinese herbs and of interferon in combination with ribavirin are in process. Several studies have reported the cost-effectiveness of interferon. Table 7.3 summarises these studies. As more has become known about interferon's impact on the natural history of hepatitis C and experience with its use has increased, so early variation in the results of these studies has given way to consensus about the cost-effectiveness of treatment.

Evidence from meta-analysis of randomised trials suggests that interferon is effective in clearing viral infection in 20 to 30 per cent of those infected, with higher response rates being achieved in younger patients, in patients without evidence of cirrhosis, and for certain genotypes. Higher rates of sustained effect are also achievable if treatment is extended from six to 12 months. Variation in effectiveness between studies often relates to differences in the clinical populations recruited to each study. In summary, the results of this work suggest the following.

- Interferon is cost saving only when future costs and savings are not discounted or when a monetary value of life is imputed into the analysis.
- Treatment results in additional years of life at what might appear to be reasonable cost.
- Extended treatment leads to better outcomes and higher total expenditures, although the incremental cost per (quality-adjusted) life-year gained does not increase (three years).

- The cost-effectiveness ratios tend to be sensitive to assumptions made about the effects on quality of life of the disease and its treatment (two studies).
- The results are sensitive to assumptions made about disease transition, especially from chronic hepatitis C to cirrhosis.

Initial results from a re-evaluation of the use of interferon in Australia suggest that its cost-effectiveness has increased substantially following reductions in the price of the drug and changes in clinical practice to exclude patients from treatment if they have failed to respond after 12 weeks (Brown et al. 1998). Preliminary results suggest that the cost per quality-adjusted life-year for six months' treatment when compared with conventional management is less than \$10 000. The *incremental* cost per quality-adjusted life-year of 12 months' treatment (that is, beyond six months' treatment) is in the order of \$40 000. Differences in the genotypes typically seen in Australia mean that treatment is generally more effective than elsewhere but this also reduces the incremental gain one receives from extending treatment from six to 12 months.

The results of this evaluation were also highly sensitive to assumptions made about the impact that both the disease and its treatment have on quality of life. Even very small changes in the effect of 12 months' treatment on quality of life were enough to change the cost-effectiveness ratios markedly, suggesting that more research into the social impact of the disease and its treatment is needed.

Finally, there is also a worrying tendency for the effectiveness of a particular treatment to be reduced as the treatment moves from being an experimental intervention to a control intervention. Thus, in evaluations that have compared conservative management with six months' treatment with interferon, rates of effectiveness of around 20 per cent have been used; in studies in which six months' treatment is the control and is compared with 12 months' treatment, effectiveness may be as low as 14 per cent (Poynard et al. 1996). In the re-evaluation discussed here a more conservative approach has been adopted, which has tended to overstate the effectiveness of the control regime relative to the experimental one. This makes the move from six to 12 months' treatment look less favourable than would otherwise be the case.

Treatment with interferon alone has already been superseded by combination therapy using interferon and ribavirin. Combination therapy increases the response rate—in one study from 18 to 36 per cent (Reichard et al. 1998). The increased effectiveness comes at additional cost, though, and it is essential that the incremental cost-effectiveness of combined treatment be evaluated. Genotyping could, in the future, be used to determine who best benefits from treatment with interferon and ribavirin.

A further development is the use of polymerase chain reaction testing to define infectiousness and so monitor the effectiveness of treatment. Response to treatment is reflected more quickly than with ALT (alanine aminotransferase) levels, allowing earlier modifications to be made to drug treatment. Then, if no response is evident after four weeks' treatment with interferon at the recommended dose, there is the option to increase the dose from the next eight weeks. PCR testing may therefore increase the effectiveness of treatment but at additional cost. Once again, it is important that its cost-effectiveness be assessed.

Table 7.3 Published economic evaluations: a summary

Study	Method	Comparison	Direct costs	Indirect costs	Outcome measure	Discounted	Results	Comments
Garcia de Ancos et al. (1990)	Decision analytic, 10 years, CHC incl. cirrhosis	3 miu / 26 weeks v conservative management	Treatment protocols, hospital unit costs, excludes capital	Production effects	Net costs Life-years Value of life (human capital)	No discounting	Interferon cost saving when production gains included	No discounting and use of human capital favours interferon
Shiell et al. (1994)	Decision analytic, 32 years, CHC incl. cirrhosis	3 miu / 26 weeks v conservative management	Treatment protocols, fee schedules	Not included	Life-years gained	Discounted 5%	Interferon costs A\$55 000 per life-year gained	Cautious modelling of benefits favours conservative management
Dushieko & Roberts (1995)	Decision analytic, 30 years, CHC incl. cirrhosis	3 miu / 26 weeks v conservative management	Treatment protocols, hospital costs, patient time and travel	Lost productivity to attend hospital	(Quality-adjusted) life-years gained & value of life (imputed)	Discounted 5%	Interferon costs per life-year ranged from £2142 to £17 128	Interferon cost saving when value of life imputed
Joliet et al. (1996) (in French)	Before and after comparison, 137 patients (77 with interferon)	3 miu / 26 weeks & 3 miu / 52 weeks v conservative management	Hospital costs of patients treated with and without interferon	Not included	Cases of cirrhosis prevented	Discounted 5%	12 mths with discontinuation in non-responders dominates	Details from abstract only
Bennet et al. (1997)	Decision analytic, mild CHC	Single course interferon over 26 weeks	Treatment protocols, adjusted charges	Not included	Quality-adjusted life-years (imputed)	Discounted 5%	Interferon costs per life-year US\$500–\$62 000	Interferon cost-effective in younger age groups
Kim et al. (1997)	Decision analytic, CHC indolent and aggressive disease	3 miu / 26 weeks v 3 miu 48 weeks by age cohort	Treatment protocols, published costs	Not included	Quality-adjusted life-years (imputed)	Costs only at 3%	Cost per quality-adjusted life-year US\$4000 (26 wks) US\$5000 (52 wks)	Discounting costs but not benefits favours interferon

7.4 Priority setting using economic analyses

There is considerable debate among economists about the role that estimates of disease cost should play in priority setting. All sides in the argument agree that priorities cannot be based solely on estimates of disease burden, but there are differing views about what else is needed. One view is that disease costs, along with other indicators of disease burden, can be used to screen potential priority areas and so allow evaluative effort to focus on those areas that will probably yield the highest gains. On the other hand, it is argued that big problems, as indicated by high burden, are not necessarily those that need to be tackled first and one should start instead from the current allocation of resources and focus on the marginal cost-effectiveness of interventions rather than the burden of disease.

The incidence-based costs of hepatitis C provide an indication of the minimum benefits that could be realised from an effective prevention campaign, although uncertainty about what works best and by how much limits the usefulness of this information. The 'burden of illness' approach to priority setting encourages one to think about the relative size of the problem rather than what can be gained by re-allocating existing resources between hepatitis C-related interventions or by the additional investment of new resources to hepatitis C-related interventions.

Uncertainty about the effectiveness of interventions hampers the setting of priorities. It is easy to call for more research into the design and evaluation of preventive interventions, but the lessons to be learnt from this research will take time to become evident. The circumstances surrounding hepatitis C transmission also make such research difficult to carry out. In the meantime, decisions need to be made about how much ought to be allocated to which methods of preventing and treating hepatitis C relative to competing demands on the public health budget.

In these circumstances, the strategy of giving priority to areas where there are demonstrably large health gains to be made relative to the additional investment required may seem too conservative. To avoid under-investing in activities that lie outside mainstream public health, Hawe and Shiell (1995) suggested taking a 'portfolio' approach to investing in health gain. The proposition is that the optimum 'public health portfolio' is one that offers a balance between different sorts of public health 'investments' in order to attempt to maximise the health return per dollar invested. Such a portfolio should include a judicious balance between blue-chip investments, which offer solid health gains at reasonable cost, and high-risk investments, which may or may not result in large health gains. The nature of hepatitis C infection and the lack of knowledge about what works to prevent its transmission put many of the potential preventive interventions into the latter (high-risk) category.

The portfolio approach builds on the program structure and marginal approach to resource re-allocation that is embodied in the program budgeting and marginal analysis method of priority setting (Mooney et al. 1996). Thus, the portfolio approach recognises that a high burden of illness is neither necessary nor sufficient reason to give priority to one set of interventions over another. But the portfolio approach provides more leeway than is currently encouraged in the program budgeting and marginal

analysis method in determining where public health interventions ought to be allocated: it allows for investment in interventions that are currently unproven but for which there is good reason to believe they might be effective. In return for this 'freedom', greater demands are placed on decision makers, program managers and researchers. It is necessary to rely much more on professional judgment to determine where resources might best be allocated, since evidence is largely unavailable, and systems are needed to help formulate such judgments in an explicit but supportive way. The portfolio approach also brings with it a greater responsibility on program advocates to allow, and program funders to fund, full evaluation of the effectiveness of programs, lest the approach degenerate into an excuse to continue support for one's favoured program. In this way, the opportunity cost of continued investment in high-risk programs remains at the forefront.

In terms of responding to hepatitis C, it is clear from the discussion in Section 7.3.1 that the needle and syringe exchange programs represent a blue-chip investment offering large health gains, financial savings, and other benefits at very low risk. Treatment with interferon also offers a reasonable health return, albeit with some uncertainty or risk associated with our ignorance about the treatment's effect on quality of life. Other preventive interventions are yet to be evaluated and must remain in the high-risk category until more is known about their effectiveness.

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Attachment I Comments on the economic analysis

A subgroup of the Review's Advisory Committee made the following comments on the economic analysis and how future analysis might be improved.

- It is necessary to differentiate between the effectiveness of hepatitis C-related activities classified within the 'high-risk' category through use of the 'portfolio' approach to investing in health gain.

Because of the difficult nature of hepatitis C research, many hepatitis C-related activities have not undergone effectiveness evaluations, leading to their classification as 'high risk' under the portfolio approach. The subgroup argues that hepatitis C-related activities in the high-risk category should be differentiated on the grounds of effectiveness since, even in the absence of evaluation data, there are rational distinctions between them.

A more accurate presentation of a portfolio of hepatitis C-related activities might be as follows.

Level of investment risk	Activities
Blue-chip investment	Needle and syringe exchange program
Medium risk	Targeted interferon treatment with increased treatment periods In the light of emerging international research, possibly combination therapy Improved skin-penetration practices Infection control in prisons
High risk	Others

The subgroup calls for further research into the effectiveness of activities in the high-risk category as well as into the marginal benefit of expansion of some activities, particularly the needle and syringe exchange program.

- A number of factors affect the cost-effectiveness of hepatitis C-related activities and further research in the following areas would improve the validity of cost-effectiveness studies.
 - The use of discounting infers that the return on investment in hepatitis C-related activities is not very high. A cost-effectiveness analysis of the impact of activities on communicable diseases in general would more accurately reflect the true health gains to be obtained by investing in these activities. The subgroup calls for such a study.
 - The quality-of-life measure of hepatitis C influences the assessment and further research into this is needed.

- Some members of the subgroup call for interferon to be used as a preventive technique, but there is a degree of concern about this approach because of the intrusive nature of the treatment and its limited success.

RESCINDED

Part Three

Australia's response to date

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8 History of hepatitis C national policy development

8.1 Development of a national response to hepatitis C

The hepatitis C virus attacks the liver. It had been known for at least 20 years that a strain of hepatitis that occasionally followed blood transfusion was neither hepatitis A nor hepatitis B. In 1988 the agent responsible in most cases was identified and named hepatitis C virus. A specific diagnostic test became available in February 1990.

After the diagnostic test became available all blood donated to the Red Cross began to be screened routinely. In December 1991 an expert working group met under the auspices of the National Health and Medical Research Council to draw up recommendations on hepatitis C screening. There was little evidence to indicate the size of the problem, but within a few years it became apparent that a large number of Australians had been exposed to the virus: 4116 cases of hepatitis C were notified in 1991; 8812 in 1992; 7573 in 1993; and 8941 in 1994.

In 1993 the Government established a joint task force of the National Health and Medical Research Council and the Australian Health Ministers Advisory Council to report on hepatitis C. The task force released its draft report late in 1993 and its final report was endorsed by the NHMRC and AHMAC in November 1994. The task force warned the Government that there was a need for public health action to combat hepatitis C. It summarised current knowledge about modes of transmission and the frequency and severity of manifestations of the disease and made recommendations relating to laboratory diagnosis, screening, control measures, education programs, and various prevention and treatment protocols.

Affected individuals called for a national response and began forming hepatitis C councils in the early 1990s. Injecting drug user groups and needle and syringe exchanges were reporting to government agencies administering the National HIV/AIDS Strategy that their clients were anxious for more information and support and wanted to know whether the education and prevention programs recommended for HIV/AIDS were adequate to protect them against hepatitis C.

Health care workers, particularly gastroenterologists, began calling for a national response to hepatitis C: they were seeing increasing numbers of people seeking advice, treatment and care and they were becoming concerned about the risk of occupational acquisition of the disease. Gastroenterologists have played an important part in developing treatment for hepatitis C and getting the disease onto the national agenda.

In response to the NHMRC–AHMAC report the Commonwealth and State and Territory governments produced a coordinated public health response in the form of the National Hepatitis C Action Plan, which was endorsed by AHMAC in October 1994 and was based on the recommendations in the taskforce report (AHMAC 1994). The Plan put forward a series of initiatives to reduce transmission of hepatitis C and to minimise the personal and social impacts on people already infected. It called for action

in four priority areas: surveillance and epidemiology; testing; clinical management and counselling; and education and prevention. In developing the Plan, the Commonwealth had consulted with health professionals, gastroenterologists, researchers, State and Territory officials, hepatitis C support groups, Haemophilia Foundation Australia, and injecting drug user groups.

In endorsing the Plan, AHMAC supported the principle that each jurisdiction would fund its areas of responsibility for implementation, including the provision of specialist clinical services. State and Territory governments developed programs, policies and models relevant to their jurisdiction. All governments acknowledged that there were links and overlap between strategies for responding to hepatitis C and programs and infrastructure under drug and alcohol services and HIV/AIDS programs. Responses to hepatitis C have been incorporated in existing education and prevention and surveillance and research infrastructure, mostly on the communicable diseases side. An AHMAC committee and an education sub-committee were established to coordinate State, Territory and Commonwealth activities.

In carrying out its responsibilities under the National Hepatitis C Action Plan the Commonwealth allocated \$3.8 million over two years beginning in 1995–96 for national surveillance and education. In 1997 this funding was included in the budget of the Public Health Division of the Department of Health and Family Services and the Government made a commitment to maintaining a similar level of funding for a further two years. In 1998 the Government announced a further funding boost of \$1.7 million for hepatitis C research and national programs.

The National HIV/AIDS Strategy 1996–97 to 1998–99 recommended that policy frameworks, funding arrangements, infrastructure, and service delivery structures for HIV/AIDS, hepatitis C and other related diseases be integrated where there are clear overlaps. This led to the main advisory committees on HIV/AIDS being reconstituted to include related diseases such as hepatitis C. The Australian National Council on AIDS and Related Diseases was re-formed in December 1996 and the Intergovernmental Committee on HIV/AIDS and Related Diseases was re-formed in June 1997. ANCARD and IGCARD ensure that where policies and programs for HIV/AIDS and hepatitis C overlap—as in the areas of education and prevention and research—a joint approach will be developed.

8.2 The context of the national response

Because the National Hepatitis C Action Plan is framed in the context of the National HIV/AIDS and National Drug Strategies, responses to hepatitis C have been shaped by policies, infrastructure and processes underpinning these two Strategies. There have been three primary influences:

- the partnership approach
- harm minimisation
- programs and policy based on research and surveillance.

8.2.1 The partnership approach

The cornerstone of Australia's response to HIV/AIDS has been a partnership between affected communities, governments at all levels, medical, scientific and health care professionals, and researchers. A basic principle in implementation of the National HIV/AIDS Strategy has been that education programs for the groups most directly affected by HIV/AIDS are best designed and delivered at the community level, by members of the target groups themselves in consultation with government agencies.

Elements of the partnership approach, which is still evolving and extending, can be seen in the response to the hepatitis C epidemic.

Early in the process of developing the national response, the National Hepatitis C Action Plan and the Nationally Coordinated Education and Prevention Approach were formulated in consultation with injecting drug user groups, hepatitis C support groups, Haemophilia Foundation Australia, governments, medical, scientific and health care professionals, and researchers. More recently, education and prevention initiatives have been delivered by the affected communities. Among these initiatives have been a hepatitis C program run by Haemophilia Foundation Australia for people with haemophilia, an assessment of the needs of people with hepatitis C undertaken by the hepatitis C councils, and the Australian Intravenous League's development of a national education program for people who use drugs illicitly. The involvement of affected communities in policy development and monitoring is evident in the membership of IGCARD and ANCARD and their sub-committees.

Central to the partnership approach is individuals' and communities' involvement in program and policy development. To date this has principally been through community-based organisations, as follows.

Support groups for people with hepatitis C (including people who inject drugs, people with a history of injecting drug use, and people with medically acquired hepatitis C) began forming hepatitis C councils in the Australian States and Territories in the early to mid-1990s. People began organising these groups in response to diagnosis, the dearth of information available, and the confusion and ignorance many people encountered. Peer-based support through the provision of hepatitis C information, phone 'buddy' systems, meetings and public information seminars stimulated local communities to form incorporated associations. The State-based hepatitis C councils define their principal task as the provision of information and referral and peer-based support services to people affected by hepatitis C. Community representation is a vital part of their work.

There has been a range of initiatives: provision of telephone support and information services, resource production, volunteer training, awareness-raising activities, lobbying and policy development, participation in health care training programs, inter-agency collaborations, media work, and so on. Some groups have also determined that primary prevention initiatives aimed at the general community was necessary and complemented the services provided by peer-based injecting drug user groups. Most groups have also recognised the importance of establishing infrastructure to meet local needs—the involvement of people with hepatitis C, injecting drug users, health professionals, counsellors and researchers in their management committees, projects

and services are good examples of community involvement and empowerment. Box 8.1 provides a more detailed history of Australian hepatitis C councils.

Peer-based injecting drug user groups formed throughout Australia in response to the National HIV/AIDS Strategy. The illicit nature of injecting rendered traditional public health approaches ineffective: user groups were funded by government to involve the communities at risk in the delivery and design of education programs, the provision of needles and syringes, and the formulation of health policy and programs. The user groups were funded to a lesser extent and later than other HIV/AIDS community-based organisations, have had interrupted histories, and in some jurisdictions have only recently received funding or operate as semi-autonomous programs within AIDS councils. These factors and local conditions have resulted in variations between the State-based groups in terms of their size, the range of services provided, their organisational style, and their ability to fully participate in the partnership approach to preventing the transmission of blood-borne viruses. All the groups are, however, characterised by their focus on facilitating the involvement of injectors in managing their own health and that of their peers.

By 1991 hepatitis C was emerging as the predominant health problem facing injectors. User groups were quick to respond, and many of them helped establish hepatitis C support groups and councils. They also developed some of the first hepatitis C education and prevention programs in Australia. The Australian IV League—representing the 10 user associations—received Commonwealth funding in 1996 to conduct an education and prevention program targeting people who inject drugs. The program is building on the programs developed by State and Territory user groups and aims to deliver uniform messages to injectors. The Australian IV League represents injecting drug users on ANCARD and at various other national forums, providing expert advice on the development of hepatitis C programs and policy.

Haemophilia Foundation Australia is the principal organisation representing people living with haemophilia and their families. It lobbies on behalf of these people and organises education and support activities for them. Many people living with haemophilia were infected with HIV and many more were infected with hepatitis C before the supply of blood and blood products became secure.

8.2.2 Harm minimisation

The concept of harm minimisation has been fundamental to Australia's drug strategy since the launching of the National Campaign against Drug Abuse in 1985; it is also fundamental to the National HIV/AIDS Strategy. When the National Hepatitis C Action Plan was being developed in 1994, there were a number of well-developed harm-minimisation approaches that were widely regarded as successful and that had the potential to be adapted to incorporate hepatitis C-related education and prevention activities for drug users. The main ones were the needle and syringe exchange program, peer-based education programs, education and prevention activities in prisons, and methadone-maintenance programs. These approaches are now the basis of efforts to prevent the transmission of hepatitis C among injecting drug users.

- The supplying of needles and syringes was introduced in Australia in the late 1980s and early 1990s to combat the spread of HIV/AIDS among injecting drug users. It was funded jointly by the Commonwealth and State and Territory governments under the National HIV/AIDS Strategy. Since July 1993 all States and Territories have had needle and syringe exchange programs, which allow for the free distribution of needles and syringes and support pharmacies that supply needles and syringes for sale. The programs are protected by legislation, as are workers in the exchanges and distributors of needles and syringes. Possession of unused needles and syringes, by themselves, is not an offence.
- Peer-based education programs involve current or past injectors as staff and volunteers in order to achieve higher levels of contact with injecting drug users and to provide non-judgmental advice about how to inject safely. User groups have developed education and prevention activities specifically directed at changing the culture, rituals and peer norms connected with unsafe injecting behaviour.
- Education and prevention activities in prisons involve education about HIV/AIDS and other blood-borne viruses. In some prisons education is delivered by peers and bleach is available for cleaning needles and syringes.
- Methadone-maintenance programs have existed since 1985 and are strongly supported as a cost-effective form of treatment. They also have the potential to reduce the spread of infectious diseases such as HIV and hepatitis C through needle sharing because they can reduce the pool of probably infected people.

8.2.3 Programs and policies based on research and surveillance

Integral to Australia's approach to public health has been Commonwealth funding of research designed to improve education and prevention programs. Both the National HIV/AIDS Strategy and the National Drug Strategy support project grants, training awards and national research centres such as the National Centre in HIV Epidemiology and Clinical Research, the National Centre in HIV Social Research, the National Centre in HIV Virology Research, the National Drug and Alcohol Research Centre, and the National Centre for Research into the Prevention of Drug Abuse.

The lack of generalisable evidence on the extent of the hepatitis C epidemic and on the effectiveness of interventions designed to prevent transmission of the virus has posed continuing problems. Policy and program developers have relied heavily on research that is an extension of other research into HIV/AIDS or illicit drugs. For example, the National Centre in HIV Epidemiology and Clinical Research has been conducting HIV and hepatitis C seroprevalence surveys of injecting drug users yearly since 1995; as part of large surveys on HIV/AIDS, the National Centre in HIV Social Research has collected data on secondary school students' and homosexually active men's knowledge about hepatitis C; the National Drug and Alcohol Research Centre has carried out a number of studies of illicit drug use in prisons; and the Macfarlane Burnet Centre in Medical Research has been able to supply incidence data for hepatitis C infection among a cohort of injecting drug users.

8.3 Responding through the mainstream health system

Much of Australia's response to the hepatitis C epidemic has occurred through the mainstream health system, principally by securing the blood supply, funding testing for hepatitis C, and providing access to treatment.

8.3.1 Securing the blood supply

Australia introduced blood screening when the hepatitis C antibody test became available in 1990 and has maintained full currency as the test has undergone various improvements to reach its current third-generation status. The risk of acquiring hepatitis C through blood transfusions is now considered minimal.

Australia relies on a volunteer non-remunerated donor system for blood. Before the screening test was introduced a variety of measures were used to safeguard the blood supply. A donor questionnaire was introduced in 1982; it was revised to become a donor questionnaire plus statutory declaration in 1984. Heat testing for factor VIII to 60 degrees Centigrade for 72 hours was also introduced in 1984. In 1990 heat treatment for factor VIII increased to 80 degrees Centigrade for 72 hours; similar treatment was extended to factor IX in 1992.

The Australian Health Ministers Advisory Council agreed to a blood transfusion service 'Look Back' policy for hepatitis C in October 1994. This involves tracing, as far as records allow, people who received blood before 1990 from donors who have subsequently been found to be hepatitis C antibody positive; tracing, as far as records allow, of donors when a recipient of blood is found to be hepatitis C antibody positive; and formally referring for counselling and follow-up prospective donors who return an indeterminate result on a test for hepatitis C.

There are a number of legal actions arising from hepatitis C infection allegedly acquired from medically transfused blood. Before a specific test for the virus was developed, the United States and some European countries elected to screen their blood with so-called surrogate markers of infection over the period 1985 to 1989. The Australian Red Cross National Blood Transfusion Committee did not endorse the use of surrogate markers, although the Queensland Blood Transfusion Service adopted them. It is on the basis that Queensland adopted the tests that other blood transfusion services are now being sued. There are also a few cases in which it is alleged that the disease was acquired in the period between the first- and second-generation antibody tests.

8.3.2 Hepatitis C testing

Testing for hepatitis C became available in 1990. Screening tests for the virus are funded through the Medicare Benefits Schedule.

Concern about the number of false positives led the Commonwealth to take steps to improve the quality of testing. Amendments to the Therapeutic Goods Act were introduced in October 1995; the Act now requires pre-market evaluation of hepatitis C

test kits and that the NHMRC Hepatitis C Working Party develop best-practice protocols for laboratory diagnosis of hepatitis C. Responsibility for assessing and approving diagnostic tests for both hepatitis C and HIV/AIDS rests with the National Serology Reference Laboratory, which is managed by the Therapeutic Goods Administration.

8.3.3 Treatment

State and Territory governments are responsible for providing treatment and care for hepatitis C–infected people living in their jurisdictions. General practitioners, immunologists, gastroenterologists and infectious diseases specialists manage patients with the infection and its sequelae.

At present, interferon is the only specific treatment approved for use in Australia for chronic hepatitis C. It was approved as a section 100 pharmaceutical under the *National Health Act 1953* in September 1994 and is available only through specialist treatment centres nominated by the States and Territories and only to patients who meet criteria specified by the Pharmaceutical Benefits Advisory Committee. The Commonwealth has an agreement with the States and Territories to fund the use of interferon in the treatment of eligible patients.

In 1997, in response to the proposals of the NHMRC Hepatitis C Working Party, the Pharmaceutical Benefits Advisory Committee recommended that access to interferon therapy be broadened to include injecting drug users and other categories of people with chronic hepatitis C and that Commonwealth support be provided for up to the first 12 months of treatment, dependent on the response to treatment. In 1996–97 Commonwealth funding for interferon therapy exceeded \$2 million.

A HepCare coordinated care trial is currently being run in Sydney using Commonwealth and State government funding. It will examine the effectiveness of a range of treatments for hepatitis C, in a range of settings, including evaluating some alternative therapies and greater GP involvement in patient management and the prescribing of interferon.

8.4 Summary

In international terms, the Australian public health system responded quickly to the hepatitis C epidemic by enhancing its education and prevention, treatment and care, and surveillance infrastructure. The following actions have been central to this response:

- securing the blood supply following the availability of a diagnostic test for hepatitis C;
- identifying the need for national public health action in response to hepatitis C by late 1993;
- developing the National Hepatitis C Action Plan in October 1994 and the Nationally Coordinated Approach to Education and Prevention in November 1995;

- integrating hepatitis C with existing public health infrastructure funded under the National HIV/AIDS Strategy and the National Drug Strategy in the areas of education and prevention and research while identifying specific gaps in the public health response;
- providing access to hepatitis C testing and treatment with interferon and developing treatment and management guidelines for health practitioners.

RESCINDED

Box 8.1 Hepatitis C councils in Australia

Support groups for people with hepatitis C (including people who inject drugs, people with a history of injecting drug use, and people with medically acquired hepatitis C), concerned health professionals, and researchers began forming hepatitis C councils in the Australian States and Territories in the early to mid-1990s. People began organising these groups in response to diagnosis, the dearth of information available, and the confusion and ignorance many people encountered. Peer-based support through the provision of hepatitis C information, phone 'buddy' systems, group meetings and public information seminars stimulated local communities to form incorporated associations.

In November 1991 the New South Wales Hepatitis C Support Group was established to provide support for people with hepatitis C in that State and to represent their interests in the broader community. A toll-free telephone line involving a network of metropolitan and regional volunteer counsellors was established and the first hepatitis C information booklet was produced and distributed to callers and health care professionals.

Recognising that there was a similar need for information and support in the other Australian States and Territories, and with the involvement of hepatitis C-affected volunteers in Western Australia, Victoria and New South Wales, the Group became incorporated in February 1993 as the Australian Hepatitis C Support Group and soon became a registered charity. While remaining committed to client support services, the Group began to give more attention to public and peer education. The Group's focus had begun to include federal matters too, such as access to interferon treatment and social security pensions. Liaison with health and welfare agencies had also increased considerably.

Submissions for federal funding were unsuccessful and the Group found it could not function at the national level, so in July 1994 it re-formed as the Hepatitis C Council of New South Wales. In the same year, NSW Health formed a Hepatitis C Taskforce and provided recurrent funding to the Council, which was able to further expand its information and support services, chiefly through the Hepatitis C Telephone Information and Support Service and resource production, including a quarterly magazine, *The Hep C Review*.

The Hepatitis C Council of Western Australia is another example of community-initiated action. Starting as support group in 1992 with the aim of providing support and referral services and information to people affected by hepatitis C, the Council broadened its objectives to lobby for a more comprehensive local response and a higher profile for hepatitis C in Western Australia. Successful in attracting temporary funding in 1993, it has been instrumental in galvanising a community-oriented, consumer-based response to meet the needs of people with hepatitis C and in promoting innovative education and prevention initiatives.

The Hepatitis C Council of Victoria was formed by volunteers in 1992 and incorporated in early 1994—it was then called the Hepatitis C Foundation of Victoria. It received recurrent funding in 1995–96. Like the New South Wales and Western Australian Councils, the Victorian group produces a wide range of resources, including a bimonthly magazine, *Good Liver*. The Hepatitis C Council of Queensland began life in 1994 as a network of people with hepatitis C, concerned health care professionals, and members of the Brisbane Hepatitis C Support Group and QUIVAA, the Brisbane-based injecting drug user group. The Council has received recurrent funding since 1995–96 and has developed and participated in numerous projects with drug user groups, youth agencies, and primary health care services. The Hepatitis C Council of South Australia was formed in 1993 as a support group for people with hepatitis C, their family members, and health professionals. Incorporated in 1994, it received funding from the South Australian Health Commission in 1996.

Box 8.1 (cont'd) Hepatitis C councils in Australia

Tasmania and the two Territories have had a much more difficult journey. The Hepatitis C Council of the ACT was formed as a support group in 1993 and became incorporated in 1996. It received a grant from ACT Health in 1998 to employ two half-time staff. The Hepatitis Network of the NT incorporated in 1997 and remains unfunded. The Tasmanian AIDS Council has formally adopted hepatitis C service provision and, to reflect this, changed its name to the Tasmanian Council on AIDS and Related Diseases in 1997.

Late in 1995 representatives of each hepatitis C organisation met under the auspices of the Commonwealth Department of Health and Family Services to discuss the feasibility of forming a national body to represent hepatitis C organisations. At the time funding was not available to support such a proposal, but the Department supported the formation of a working party to conduct a national assessment of the needs of people with hepatitis C. In August 1996 Burrows and Bassett completed *Meeting the Needs of People in Australia Living with Hepatitis C*, which had been funded by the Department under the direction of a National Hepatitis C Councils Reference Group.

All this activity paved the way for the development of the Australian Hepatitis Council Inc., which incorporated in the Australian Capital Territory in 1997 as the national body representing hepatitis C organisations. A funding proposal to the Department of Health and Family Services early in 1998 resulted in a grant to the Council to provide a number of education-based initiatives. The Council has since established an office in Canberra under an agreement with the Public Health Association (Inc.) and since October 1998 has had two full-time employees. The Council is developing an education strategy and several education projects.

Most hepatitis C organisations have received limited and sporadic funding from government, the private sector and charities or have raised their own funds to provide support services and awareness-raising activities. Activity has mostly occurred in metropolitan areas: there has been limited activity in rural and remote Australia. It remains a challenge for many of the councils to provide services in these areas, often because they lack the resources to respond to regional problems. All organisations have sought funding from their jurisdiction's department responsible for health.

The various State and Territory hepatitis C organisations define their primary business as the provision of information and referral and peer-based support services to people affected by hepatitis C. Community representation is a vital part of their work. There have been a range of initiatives: provision of telephone support and information services, resource production, volunteer training, awareness-raising activities, lobbying and policy development, participation in health care training programs, inter-agency collaboration, media work, and so on. Some groups have determined that primary prevention initiatives targeting the general community are necessary and complement the services provided by peer-based injecting drug user groups. Most groups have also recognised the importance of establishing infrastructure to meet local needs—the involvement of people with hepatitis C, injecting drug users, health professionals, counsellors and researchers in their management committees, projects and services are good examples of community involvement and empowerment.

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RESCINDED

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9 Implementation status of the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach

This overview of the implementation status of the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach is based on the results of a survey sent to State and Territory health departments and the Commonwealth Department of Health and Aged Care. The results cover the period October 1994 to March 1998, although not all activities that have been undertaken are discussed.

The chapter is in three main sections. The first describes the method used to determine implementation status; the second looks at the National Hepatitis C Action Plan; and the third looks at the Nationally Coordinated Hepatitis C Education and Prevention Approach. The second and third sections summarise health departments' perceptions of the Action Plan and the Education and Prevention Approach and briefly describe the main implementation themes and the degree to which each recommendation has been implemented. Appendix B provides detailed information about implementation.

9.1 Method

The Commonwealth Department of Health and Aged Care developed a survey instrument and sent it to State and Territory representatives on the Intergovernmental Committee on AIDS and Related Diseases, asking them to coordinate a response on State and Territory action in keeping with the recommendations of the two documents detailing the Action Plan and the Education and Prevention Approach.

The survey asked three broad questions about each document.

- i. Did the Department work to the recommendations?
- ii. How were the recommendations prioritised?
- iii. Did the recommendations provide a useful way to respond to the hepatitis C epidemic?

A further four questions were asked about each of the 32 recommendations contained in the documents.

- i. Identify your State/Territory's activities in respect to each recommendation.
- ii. To what extent was each recommendation implemented? (Not at all/Fully/In part/Will be/Other)
- iii. Describe the outcome of its implementation (ie actions undertaken).

- iv. In your assessment, was the implementation effective? (Very/Moderately/Not at all)

All State and Territory health departments and the Commonwealth Department of Health and Aged Care responded, providing the basis of this chapter. The survey results provide a good picture of Australia's response to hepatitis C from October 1994 to March 1998, although the quality of the responses varied as a result of resource constraints and the time needed to complete the survey. That is why the list of activities is not exhaustive.

Further, the measure of the implemented recommendations' effectiveness is based on self-reporting by each jurisdiction. Since most activities have not been evaluated the effectiveness measure is subjective.

9.2 The National Hepatitis C Action Plan

9.2.1 Overview

From the perspective of State, Territory and Commonwealth health departments, most of the recommendations in the Action Plan document have been implemented, although with moderate effectiveness. Most State and Territory health departments claimed the document had provided a good background on hepatitis C and a formal mandate and framework for action, but they noted continuing gaps and the need for further work.

9.2.2 Epidemiology and surveillance

In relation to epidemiology and surveillance, the National Hepatitis C Action Plan recommended as follows:

- 1 Use by the Commonwealth and all States and Territories of an appropriate and consistent definition of incident and prevalent cases of hepatitis C
- 2 Improved surveillance through a 12-month pilot study involving: active follow-up of seropositive tests to enable the optimal ascertainment of incident cases; collection of information on risk factors for incident and prevalent cases
 - 3.1 Systems operating for following up reports of cases of hepatitis C infection and collection of surveillance data
 - 3.2 Uniform minimum data set developed and the collation and reporting of national data in *Communicable Diseases Intelligence*.

According to State and Territory health departments and the Commonwealth Department of Health and Aged Care, these recommendations have largely been implemented, but with modest results because of a number of persistent methodological problems.

The definition of hepatitis C diagnosis was agreed to by CDNANZ (the Communicable Diseases Network of Australia New Zealand) and was adopted for the recording of incident cases of hepatitis C in the National Notifiable Diseases Surveillance System

and in the nationwide surveillance pilot in 1995. (The pilot was implemented in all States and Territories but Queensland, which had already conducted a similar pilot.)

Results of the surveillance pilot were published in *Communicable Diseases Intelligence* (Andrews & Curran 1996). From the notifications received, an incidence rate of 7.8 cases per 100 000 population was estimated for 1995. The estimate is, however, unreliable for a number of reasons, among them the variation in methods used by the States and Territories, response bias, and the presence of duplicates among the notifications. Only a small proportion of incident cases of hepatitis C develop clinical hepatitis, so the detection of newly infected cases is difficult. The report in *Communicable Diseases Intelligence* concluded that routine surveillance may not be the most appropriate mechanism for gathering detailed epidemiological data on hepatitis C.

In addition, participating States and Territories found the methodology labour intensive. Many positive tests had to be followed up in order to differentiate the relatively low number of incident cases from the prevalent cases. They claimed that other approaches for estimating the incidence of hepatitis C in the Australian community should be considered; for example, sentinel screening programs and studies in selected cohorts.

In response to the recommendations of the surveillance pilot, the National Centre in HIV Epidemiology and Clinical Research is being contracted, under the auspices of CDNANZ, to conduct national surveillance of hepatitis C in Australia. This will include the development of a national strategy for hepatitis C surveillance and the establishment of a CDNANZ hepatitis C surveillance reference group. Among specific surveillance activities will be the collection, analysis and dissemination of data from injecting drug users attending needle and syringe exchanges and methadone clinics as well as some groups of health care workers, such as those who have sustained a needlestick injury. This will build on the work the Centre has been doing, including the annual needle and syringe survey. Protocols will also be developed for hepatitis C surveillance in other population groups, such as the defence forces, blood donors and pregnant women.

9.2.3 Hepatitis C testing

In relation to hepatitis C testing, the National Hepatitis C Action Plan recommended as follows:

- 4 The National HIV Reference Laboratory coordinates technical aspects of hepatitis C laboratory testing including evaluation of test kits, quality control and quality assurance programs, and standard setting
- 5 The Therapeutic Goods Administration has in place measures to evaluate and approve hepatitis C test kits as a condition of entry on the Australian Register of Therapeutic Goods
- 6.1 Approved first line tests for hepatitis C infection are widely available to pathology laboratories

- 6.2 Specialised tests are available, with limitations on which laboratories are approved to conduct particular test being consistent with testing protocols and TGA requirements
- 7 The existence of appropriate protocols for the conduct of testing, addressing clinical and public health indications for testing, and which tests should be performed in specific circumstances.

According to the Commonwealth Department of Health and Aged Care, which was responsible for their implementation, these recommendations have been fully implemented, with what is considered to be moderate effectiveness.

On behalf of the Commonwealth, the National HIV Reference Laboratory in Melbourne is responsible for pre-market evaluation of the performance of hepatitis C test kits and post-market monitoring of kits in use. The quality assurance program for viral-load testing has been only partially instituted but a recent Commonwealth grant for the project will ensure its completion.

Since 1 October 1995 in-vitro diagnostic goods for the diagnosis of patients infected with hepatitis C have been required to be registered in the Australian Register of Therapeutic Goods.

The supply of hepatitis C test kits is unrestricted once the tests are approved as first-line tests and are on the Register of Therapeutic Goods. Supplementary test kits are those based on nuclear technologies such as polymerase chain reaction or DNA testing; these are authorised for use in laboratories specified by State and Territory health authorities in accordance with criteria developed by the National Health and Medical Research Council's Hepatitis C Working Party. State and Territory health authorities are responsible for determining laboratory competencies and ensuring that the criteria are uniformly applied. The Commonwealth Therapeutic Goods Administration's role is to ensure that the sponsors of registered kits supply only approved laboratories.

The development of protocols for testing, the clinical and public health indications for testing, and which particular test should be performed in which circumstances is part of the work of the NHMRC Hepatitis C Working Party. The Working Party released *A Strategy for the Detection and Management of Hepatitis C in Australia* in September 1997. That document examined the characteristics and transmission of the hepatitis C virus, screening and surveillance, laboratory testing, clinical indicators for testing, and clinical protocols (including counselling guidelines).

Findings from the National Reference Laboratory suggest that, despite the release of the strategy document, inappropriate hepatitis C testing mechanisms are being used; the Laboratory claims the mechanisms should be consistent with those used nationally for HIV testing. The data suggest serious shortcomings with the anti-hepatitis C assays in that both false negative and false positive results are observed with all tests.

The National Reference Laboratory has worked with individual laboratories to ensure consistency in the use of PCR technology, but State and Territory policies relating to authorisation and monitoring of laboratories doing PCR testing vary considerably and the lack of a consistent approach contributes to the shortcomings in testing.

Over 1.3 million tests for hepatitis C have been recorded for the Medicare Benefits Schedule since July 1993. It is difficult to identify the precise number of tests because investigations for hepatitis C are often done at the same time as investigations for other forms of hepatitis: investigations for multiple forms of hepatitis carry the same Medicare item numbers (69265, 69274, 69277, 69278, 69280, 69281 and 69283). The Department of Health and Aged Care has estimated that there were 163 085 hepatitis C-related tests in 1993–94; 292 521 in 1994–95; 245 205 in 1995–96; 293 572 in 1996–97; and 337 982 in 1997–98.

The National Centre in HIV Epidemiology and Clinical Research's national survey of injecting drug users attending needle and syringe exchanges has found that many injecting drug users report being tested for hepatitis C: in 1995, 77 per cent of injecting drug users reported having been tested; in 1996 the figure was 80 per cent and in 1997 it was 84 per cent (NCHECR 1995, 1996, 1997).

It also appears that a greater percentage of injecting drug users who report already having been tested for hepatitis C have been exposed to the infection: 68, 71 and 56 per cent (for 1995, 1996 and 1997 respectively) were found to have been exposed to hepatitis C infection. This compares with 44, 40 and 14 per cent of injecting drug users who report never having had a hepatitis C test but have been found to be exposed to the virus.

9.2.4 Management, counselling and treatment of patients

In relation to the management, counselling and treatment of patients, the National Hepatitis C Action Plan recommended as follows:

- 8.1 Adequate and appropriate counselling and referral services are available
- 8.2 Provision of counselling by suitably qualified health care workers to persons who have positive hepatitis C tests or whose status remains indeterminate
- 8.3 Referral of newly diagnosed positive and indeterminate patients to suitably qualified medical practitioners for follow-up
- 9.1 Diagnosis and clinical guidelines developed for the management of antibody positive or antibody indeterminate patients and the management of interferon
- 9.2 Wide availability of professional development opportunities for medical and other health professionals, linked to diagnosis and clinical guidelines
- 10 Assistance to appropriate community based groups to address the support needs of people with hepatitis C.

According to State and Territory health departments and the Commonwealth Department of Health and Aged Care, these recommendations have been fully or partially implemented, with moderate effectiveness.

Among actions in this area have been the setting up of telephone help lines; provision of funding to hepatitis C councils; provision of support services, often through drug and alcohol services; group education; and information sessions.

There are, however, numerous continuing problems: inadequate pre-treatment information; inadequate counselling for interferon recipients; the impossibility of ensuring that all GPs are suitably trained and can counsel patients effectively; some service providers' negative attitude to people with hepatitis C, particularly those who continue to inject drugs; lack of ongoing funding; inadequate provision of counselling; and poor access by migrants, Indigenous Australians, prisoners and their families, and clients of mental health services.

9.2.5 A national approach to education and prevention

In relation to a national approach to education and prevention, the National Hepatitis C Action Plan recommended as follows:

- 11.1 A document outlining a coordinated national education approach with input from the Commonwealth, States and Territories, and community and professional groups
- 11.2 Review conducted of number and type of education materials and training packages relating to hepatitis C (as at October 1994)
- 12.1 Review conducted in late 1994/early 1995 of current education strategies for youth, injecting drug users, people with hepatitis C and health service providers, including drug and alcohol programs, to take account of hepatitis C
- 12.2 Review in late 1994/early 1995 of occupational health and safety guidelines on exposure to blood and body fluids regarding adequacy to deal with hepatitis C
- 13 Increased availability of sterile injecting equipment.

According to State and Territory health departments and the Commonwealth Department of Health and Aged Care, most of these recommendations have been fully or partially implemented, but their effectiveness is unmeasured. Some States claim that important aspects of the Approach have not been implemented, particularly recommendations 11.2 and 12.2, although most States have taken action on the latter recommendation.

Among the actions that have been taken are the development of the Nationally Coordinated Hepatitis C Education and Prevention Approach, which has been implemented to various extents in different States and Territories (see Section 9.3); the establishment of national committees such as the ANCARD Hepatitis C Sub-committee, the ANCARD Education Sub-committee, the IGCARD Education Managers Forum, and the IGCARD Hepatitis C Education and Prevention Working Party; and the development of some national resource material.

State and Territory submissions identified the following problems: lack of funds allocated to the area; no agreement about an appropriate national media strategy; the fact that the States and Territories are at different stages of work on various strategies; some state school systems opposing education on injecting drug use; the absence of a

formal review of education approaches; and deficiencies in reaching young people and developing resource material.

The number of needles and syringes available continues to increase but there are serious gaps in geographical and temporal availability. Some jurisdictions have coped with large supply increases without increases in funding but this has often come at the expense of other services; for example, the provision of education.

9.3 The Nationally Coordinated Hepatitis C Education and Prevention Approach

In the main, State and Territory governments have implemented many of the recommendations in the document describing the Nationally Coordinated Hepatitis C Education and Prevention Approach. Areas implemented vary between jurisdictions, this being mainly determined by what could be implemented without additional resources and, in many States and one Territory, by priorities developed through consultation with interested parties.

Although the Approach was deemed useful, most jurisdictions developed their own strategies after a national workshop on the subject and before the workshop recommendations were published. Submissions to the review were critical of the lack of clarity in relation to the roles and responsibilities of the various organisations with an interest in hepatitis C.

Despite this, and despite continuing gaps in areas of activity, the States and Territories have done a great deal—Appendix B provides details.

9.3.1 Injecting drug users

In relation to injecting drug users, the Nationally Coordinated Hepatitis C Education and Prevention Approach recommended as follows:

- 1.1 Enhanced needle and syringe exchange program achieved through development of outreach and other options to maximise access
- 1.2 Information resources and peer education interventions developed
- 1.3 Harm minimisation strategies promoted
- 1.4 Methadone programs expanded
- 1.5 Policies for hepatitis C education and prevention programs developed
- 1.6 Coordinated planning of hepatitis C education and prevention policy and programs

These recommendations have been implemented either partially or in full in all jurisdictions, although further work is needed and the interventions' effectiveness remains largely unmeasured and unknown.

The State and Territory submissions identified a number of continuing problems in this area:

- geographical and temporal gaps—for example, the lack of needle and syringe distributors in rural areas and outside business hours;
- legal, political and attitudinal barriers to appropriate prevention strategies—the illegality of injecting drug use continues to be a major barrier to the delivery of appropriate preventive services and education;
- the shortage of general practitioners able to prescribe methadone treatment;
- the lack of methadone treatment in prisons;
- the lack of education and prevention measures targeting young people and people just beginning to inject drugs;
- the absence of a national or State model for managing hepatitis C that integrates action taken on HIV/AIDS and related diseases with action taken on alcohol and other drugs—this is problematic because these services deliver the majority of hepatitis C education and prevention programs;
- continuing inter-agency confusion and rivalry about the mandate and resources available;
- inadequate updating of hepatitis C-related educational material despite significant changes to the content of information on the subject;
- pessimism among injecting drug users and health care workers about the effectiveness of hepatitis C prevention strategies and fatigue among health care workers;
- in non-specialist hepatitis C services, a common perception that hepatitis C is not a priority for health care workers, which is compounded by the fact that the general community does not see hepatitis C as a priority.

The number of people undergoing methadone-maintenance treatment doubled from 1993 to 1998—in 1993 there were 12 989; in 1994 there were 14 996; in 1995 there were 17 356; in 1996 there were 19 573; in 1997 there were 22 239; and in 1998 there were 24 657. In 1998, 6 per cent of clients received methadone-maintenance treatment from public clinics; the remainder were treated by private medical practitioners (Department of Health and Aged Care 1999).

The National Centre in HIV Epidemiology and Clinical Research's national survey of injecting drug users attending needle and syringe exchanges suggests that in 1997 a decreasing proportion of injecting drug users were engaging in behaviours that place them at risk of transmission of HIV, hepatitis B and hepatitis C (MacDonald et al. 1998). In 1995, 31 per cent of injecting drug users had used a needle and syringe after someone else in the preceding month; in 1996, 28 per cent had done so; in 1997, 18 per cent had done so. Although these apparent improvements in safe injecting practice are encouraging, if these and other studies carried out between 1985 and 1998 are

examined closely the picture of change is not so clear—see, for example, Figures 6.1 to 6.4.

The number of needles and syringes distributed from 1994–95 to 1996–97 has increased significantly—see Table 9.1.

Table 9.1 Number of needles and syringes distributed, by State and Territory, 1994–95 to 1996–97

Year	1994–95	1995–96	1996–97
New South Wales	5 834 937	6 396 428	8 165 044
Victoria	3 091 000	3 023 000	3 093 000
South Australia	648 385	910 291	1 244 220
Western Australia	1 705 558	1 392 434	1 695 274
Northern Territory	119 300 ^a	144 764 ^b	198 690
Queensland ^b	2 044 993	3 119 986	3 780 200
Tasmania	181 206	206 746	292 781
Australian Capital Territory	313 845	360 595	540 679
Total	13 939 224	15 554 244	19 009 888

a. Average monthly figures used for months missing data.

b. Calendar years 1995, 1996 and 1997.

Source: Department of Health and Aged Care.

9.3.2 Skin penetration

In relation to skin penetration, the Nationally Coordinated Hepatitis C Education and Prevention Approach recommended as follows:

- 1 Infection control and safe practice training programs provided for environmental health officers and skin penetration practitioners
- 2.2 Education materials (print and audio-visual) developed for specific target groups
- 2.3 [Revision of] legislation and standards regulating infection control practices for skin penetration activities
- 2.4 Policy approaches to work practices of skin penetration practitioners developed by environmental health officers.

Much of this work is being implemented. Areas of concern or requiring more work are the targeting of acupuncturists, hairdressers, barbers and beauticians and difficulty reaching 'backyard' and rural skin-penetration businesses.

9.3.3 The general community

In relation to the general community, the Nationally Coordinated Hepatitis C Education and Prevention Approach recommended as follows:

- 3.1 National Hepatitis C Awareness Week established

- 3.2 Education of health and other appropriate journalists conducted
- 3.3 Strategic associations established with key dental and medical associations and community-based organisations
- 3.4 Public relations strategy developed, including media kits.

Very little work has been done in relation to this recommendation, mainly because there is no national consensus about its merits and many jurisdictions consider it the least pressing of the recommendations. The Commonwealth and some States and Territories have developed or are developing pamphlets aimed at the general community; an example is the Commonwealth's Schools Blood Borne Virus project. In all States and Territories resource material for hepatitis C-positive people is available to the general public.

9.3.4 Decision and policy making

In relation to decision and policy making, the Nationally Coordinated Hepatitis C Education and Prevention Approach recommended as follows:

- 4.1 Hepatitis C issues incorporated onto the agendas of HIV/AIDS Parliamentary Liaison Groups
- 4.2 Regular national hepatitis C forums on prevention, treatment and care, surveillance and policy
- 4.3 Relevant health and other conferences utilised to raise hepatitis C awareness
- 4.4 Hepatitis C as a regular agenda item of AHMAC and other high-level policy meetings (Ministerial Council on Drug Strategy, ANCARD, NHMRC).

These recommendations have largely been implemented and the national committees established are reported as being effective, particularly as an information source.

9.3.5 Custodial institutions

In relation to custodial institutions, the Nationally Coordinated Hepatitis C Education and Prevention Approach recommended as follows:

- 5.1 Availability of decontamination measures increased and availability of the means of prevention
- 5.2 Education services to inmates including training of inmates, peer education and production of resources
- 5.3 Staff trained in infection control and prevention of transmission
- 5.4 Policy for hepatitis C education and prevention developed, planning for education and prevention programs conducted.

Most States and Territories have provided some decontamination measures, prevention means and education services to inmates in some custodial institutions, the effect of which is largely unknown. Some States are trialling methadone programs.

Little has been done in the areas of staff training in infection control and prevention of transmission and in policy and program development.

Submissions noted that continuing problems with hepatitis C in custodial institutions are of major importance given the high incidence of the virus believed to exist in prisons. Two main problems were identified:

- inmate's access to effective preventive measures, such as sterile needles and syringes and methadone programs—access to these facilities is inequitable compared with the general community but such access poses many difficulties in terms of security. Some States are reviewing their stance on this. An intersectoral, non-partisan approach would be beneficial;
- preparing for the future clinical needs of inmates with acute hepatitis C.

There was a call for inmates to receive hepatitis A and B vaccinations to reduce the impact of possible co-infection with hepatitis C. Other suggestions involved ceasing to use urine tests to detect marijuana, which anecdotal evidence shows leads to inmates injecting heroin instead because it is not detected in urine tests; and development of a database to track staff and inmates living with hepatitis C.

Submissions were also received from the Queensland Corrective Services Commission, the ACT Attorney-General's Department, ACT Corrective Services, South Australian Department for Correctional Services, and the New South Wales Department of Corrective Services. The main points raised in these submissions were that injecting drug users are greatly over-represented in the prison system and so prisons endorse moves aimed at prevention, education and treatment. The submissions emphasised the need to continue close working relationships between correctional services and health departments.

9.3.6 Health service providers

In relation to health service providers in general, the Nationally Coordinated Hepatitis C Education and Prevention Approach recommended as follows:

- 6.1.1 Education materials developed and disseminated
- 6.1.2 Training programs in prevention issues, lifestyle/behavioural change, and counselling and referral developed and implemented
- 6.1.3 Supportive institutional policies developed.

Most States and Territories reported that these recommendations had been partially or fully implemented, but this mainly concerns the development and dissemination of education materials. Less work has been done on training programs on prevention and the development of supportive institutional policies, although the situation differs from

State to State; Western Australia, for example, has developed specific guidelines for various occupational groups.

Burrows and Bassett (1996) found that there was still a need for access to well-educated GPs who understand hepatitis C–positive people's condition and that GPs had very negative attitudes towards injecting drug users, which creates a barrier to the delivery of services such as adequate pre- and post-test counselling. Most States and Territories have offered GP training, and the Royal Australian College of General Practitioners hepatitis C education project, currently being commissioned by the Commonwealth, will help redress this problem.

Other problems cited by the National Hepatitis C Education Program for General Practitioner's Reference Group concerned the sporadic nature of training for health service providers; the lack of knowledge of education initiatives across States and Territories, which inhibits the use of best-practice models of education for health professionals (a matter being raised through the IGCARD Hepatitis C Education and Prevention Working Party); the lack of a booklet providing appropriate referral information; the need to coordinate hepatitis C–related training; and the general lack of knowledge about hepatitis C among a range of types of service providers whose work necessitates some knowledge of the virus.

Education for treatment, care and support

In relation to educating health service providers about treatment, care and support, the Nationally Coordinated Hepatitis C Education and Prevention Approach recommended as follows:

- 6.2.1 Referral networks of suitably qualified counsellors implemented
- 6.2.2 Education and training program for counsellors and psychologists developed
- 6.2.3 Training programs on hepatitis C counselling for GPs developed
- 6.2.4 Economic impact of hepatitis C investigated and documented.

Referral networks of suitably qualified counsellors have not been formally implemented in all States and Territories. Health care workers tend to refer to services in an ad hoc way, on the basis of their personal knowledge of services available.

Some training is available for counsellors and psychologists, although some States and Territories did not see this as a pressing need because of the good skills counsellors already possess, particularly in the drugs area.

All States and Territories have developed training programs on hepatitis C counselling for GPs, but there are a number of problems: prejudice about and fear of injecting drug users; constraints on GPs' consultation times; and lack of knowledge if hepatitis C is not a GP's particular interest. The Royal Australian College of General Practitioners project currently being developed will help resolve these problems.

In general, training tends to be ad hoc and to vary in quality. The main criticism is the continuing confusion about the roles and responsibilities of the States and Territories and the Commonwealth in providing education.

Prevention of occupational exposure

In relation to the prevention of occupational exposure among health service providers, the Nationally Coordinated Hepatitis C Education and Prevention Approach recommended as follows:

- 6.3.1 Curriculum development and in-service training for health service providers
- 6.3.2 Infection control procedures and workplace policies developed
- 6.3.3 Intersectoral collaboration on nationally agreed policy direction and utilisation of existing program arrangements.

Curriculum development and in-service training for health service providers tends to be ad hoc, with possible gaps lying in education for nurses and people working in nursing homes, mental health institutions and services in rural areas.

Most States and Territories have updated or are in the process of updating their infection-control policies; the matter is also covered through many existing procedures such as hospital accreditation.

The Australian Reference Centre for Hepatitis C Information and the National Needlestick Injury Hotline are being developed to provide occupational health and safety information and support for health service workers.

9.3.7 People affected by hepatitis C

In relation to people affected by hepatitis C, the Nationally Coordinated Hepatitis C Education and Prevention Approach recommended as follows:

- 7.1 Appropriate support services developed: peer education, specialist counselling through relevant community and government services, telephone counselling
- 7.2 Referral network for hepatitis C-positive people developed to deal with discrimination issues, social support, family counselling and advocacy
- 7.3 Education materials and services (information and referral services, support groups, for health monitoring and maintenance developed.

These recommendations have been partially implemented in most States and Territories; they mainly relate to the work of hepatitis C councils and alcohol and other drug counselling services.

Deficiencies remain, however, as noted elsewhere: geographical inequity; support for people with hepatitis C who continue to inject; support and education for all people with hepatitis C, not just those newly diagnosed; resource material for people from culturally and linguistically diverse backgrounds; GPs not linking clients with counselling services; unmet demand for family counselling for people with and affected

by hepatitis C; mainstream services still not adequately informed about hepatitis C; and continuing confusion about the roles of the Commonwealth and the States and Territories.

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Part Four

The review findings

RESOUNDING

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10 The current response to hepatitis C: a summary

This chapter summarises the review's findings in relation to the strengths and weaknesses of Australia's response to the hepatitis C epidemic and the opportunities and threats that lie ahead. Recent developments beyond the scope of the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach are also discussed.

10.1 The overall response

By international standards, Australia is considered to have responded well to the threat posed by hepatitis C. The National Hepatitis C Action Plan, developed in 1994, placed hepatitis C on the Australian public health agenda. Most States and Territories have also developed their own initiatives for responding to the threat.

10.1.1 The national response

Incorporation of hepatitis C in the National HIV/AIDS Strategy has enhanced the legitimacy of hepatitis C as a serious public health concern and given a certain focus to the national response. The Australian National Council on AIDS and Related Diseases has assumed a leadership role in relation to hepatitis C, and the partnership approach between government, the community and health care professionals is becoming more visible. In recognition of hepatitis C-related needs, the Commonwealth Government has recently allocated an additional \$1.7 million for research and national programs.

Some of the broad directions set out in the National Hepatitis C Action Plan document retain a good deal of relevance, but in other respects the document has become dated, reflecting what was needed four years ago. The National HIV/AIDS Strategy 1996–97 to 1998–99 does not describe what strategies should be adopted to meet the challenges now posed by the hepatitis C epidemic. A clear, current, national agenda for hepatitis C has not been put to interested parties—national organisations, State and Territory organisations, community based organisations, correctional services, regional health authorities, professional organisations, and so on.

10.1.2 State and Territory responses

To date, State- and Territory-based strategies have been only partially implemented. This is a consequence of a range of factors, among them a shortage of funds caused by intense competition for public health resources, a lack of community and media support, and a lack of political will. There has been only limited intersectoral action in areas such as corrections, juvenile justice and schools. Integration of hepatitis C-related matters into the drug and alcohol sector has also been limited in most jurisdictions. It should, however, be acknowledged that at the local level in many jurisdictions drug and alcohol agencies have responded well to the hepatitis C threat.

In spite of the activity that is taking place, there is a perception of a lack of impetus and that coordination of effort could be more effective. Some initiatives appear to be piecemeal or ad hoc.

10.1.3 Marginalisation of the response

The stigma associated with hepatitis C as a result of its association with injecting drug use remains strong in the minds of communities, policy makers and politicians. Many with an interest in the problem see this as contributing to hepatitis C not being afforded sufficient priority as a national public health concern.

Discrimination against injecting drug users and people with hepatitis C is reportedly common. Apart from the adverse personal impacts of this, it leads to non-disclosure, which reinforces the disease's invisibility from the point of view of the general community, thus intensifying marginalisation.

Public awareness of hepatitis C has not been adequately dealt with.

10.2 The basis for a renewed approach

Our understanding of hepatitis C—particularly in terms of its epidemiology, the challenges associated with prevention, and the needs of those infected—has improved greatly since the development of the National Hepatitis C Action Plan. This provides a good basis for moving forward.

This improved understanding of the nature of hepatitis C and its similarities to and differences from HIV and other types of hepatitis allows us to refine our approach and consider how any relationships should be reflected in services and programs. Such an approach is reinforced by the move away from disease-specific program barriers. At the program funding and planning level, it is possible to take a broader approach. The National Public Health Partnership has the potential to provide an integrating mechanism to deal with problems such as hepatitis C that cut across different national strategies.

10.3 Education and prevention

10.3.1 Established principles and infrastructure

By the time hepatitis C was recognised, harm minimisation was an established principle in the approach to illicit drugs and an infrastructure of standard prevention services—needle and syringe exchanges, methadone programs, and education programs for injecting drug users—already existed. Community-based organisations—user groups and, more recently, hepatitis C councils—have been funded in most jurisdictions.

The reach of prevention services has been extended through a significant expansion of the number of needles and syringes distributed in all jurisdictions and an increased number of methadone-maintenance places in some jurisdictions.

In spite of this, perceptions of waning political commitment to harm minimisation as an effective strategy in relation to illicit drugs and blood-borne diseases may be indicative of an unwillingness to implement a more effective approach, which is essential if the hepatitis C epidemic is to be brought under control in Australia.

10.3.2 The effectiveness of education and prevention interventions

Some studies have reported a noteworthy decline in the prevalence of needle and syringe sharing since the introduction of the needle and syringe exchange program. There is, however, also evidence that many injecting drug users continue to share, at least occasionally.

The continuing high hepatitis C incidence rate suggests that education and prevention programs have not been sufficiently effective. It may be that the output and reach of standard prevention programs such as the needle and syringe exchange program are inadequate. Alternatively, programs may be misdirected in their targeting or there may be other problems associated with the design of interventions.

There has been insufficient social and behavioural research to guide the development and refinement of education and prevention programs.

10.3.3 Challenges in education and prevention

Injecting drug users constitute a diffuse group, both geographically and socially, and there is no identifiable, coherent community. This makes access difficult and limits the range of appropriate education strategies. The education task of user groups is also made more difficult by the illicit nature of injecting drug use and limited evidence about what is good practice for education and prevention. Another factor that contributes to the challenge of education and prevention is the lack of community and political support.

Prisons are regarded as particularly high risk environments for hepatitis C transmission because of the over-representation of injecting drug users and the lack of sterile injecting equipment. Tattooing with non-sterile equipment is also thought to be a major risk factor for prisoners. Nonetheless, prisoners in each jurisdiction receive at least some hepatitis C education, although its adequacy has been questioned.

Recent Commonwealth funding of the national community-based organisations—the Australian Intravenous League and the Australian Hepatitis Council—has the potential to greatly enhance the national response to hepatitis C by providing an infrastructure for the development of national programs, linked to work taking place on the ground in the States and Territories.

10.4 Treatment and care

10.4.1 An agreed approach to testing

If estimates of hepatitis C prevalence are correct, a very large number of people with the virus have not as yet been diagnosed. There is no agreed national policy that promotes testing of people at risk, although it is common practice for injecting drug users in contact with the health care system to be offered testing.

10.4.2 Access to treatment and care

Liver clinics operate in a number of hospitals in each State and Territory. The funding of clinical nurse consultant positions in some liver clinics has done much to improve the coordination of care and the availability of information and counselling. But only a small proportion of patients are making use of tertiary-level care because the treatment options currently available are limited. For those who are eligible, access to hospital-based liver clinics can be restricted by long waiting lists and the limited geographical distribution of services, particularly in regional and rural Australia. There does not appear to be any planning to accommodate a possible increase in demand for services resulting from improved treatments and the ever-growing pool of people with hepatitis C infection.

The recent liberalisation of eligibility criteria for treatment with interferon will allow access to a wider range of people, including injecting drug users.

10.4.3 Development of primary care

General practitioners are well placed to provide primary care to people with hepatitis C because for many infected people care is currently limited to monitoring, providing education, and treating hepatitis C as part of general health care. The group currently at greatest risk of hepatitis C infection—injecting drug users—often have a variety of health care needs that extend beyond hepatitis C, but they have poor access to treatment and support services as a result of lifestyle and psychosocial factors and their marginalisation within the broader community.

The primary health care response to hepatitis C has been inadequate, particularly in terms of meeting the needs of injecting drug users. The number of general practitioners with sound hepatitis C knowledge and an interest in and sensitivity to injecting drug users is relatively low.

National and State-based shared-care models, developed to encourage general practitioners' involvement in hepatitis C medicine, are designed to improve practitioners' knowledge and skills and make high-quality care more widely available. Considerable effort has been devoted to GP education in some jurisdictions, but the potential exists for greater GP involvement in hepatitis C medicine to meet the primary health care needs of injecting drug users and other affected groups.

11 According hepatitis C sufficient priority

11.1 Is there a case for doing more to combat hepatitis C?

By international standards Australia may have responded well to the threat posed by hepatitis C, but many of those interviewed as part of this review were of the opinion that the virus is currently accorded insufficient priority in the areas of public health, treatment and care, and research. They claimed that according hepatitis C greater priority is essential if the national response is to be more effective.

Of course, determining priorities is a complex matter that cannot be done in isolation from competing demands. There are no clear processes in any Australian jurisdiction for determining the priority that should be accorded public health concerns such as hepatitis C. Nonetheless, the broadbanding of public health funds raises the question of whether allocations to those areas previously in receipt of dedicated funding can be justified in terms of both outcomes achieved and competing demands from other areas, which may be under-resourced. This is creating pressure to deal more effectively with the matter of priority determination.

Although the need to determine relative priorities is ultimately unavoidable, arising as it does at critical points such as during budget allocation, it is important to avoid seeing priority determination simply in terms of a disease 'pecking order'. The new emphasis on the partnership approach to public health recognises that actions to tackle particular problems—and hepatitis C is just one example—can be much more effective if a more integrated approach to a range of public health concerns is taken. Rather than seeing hepatitis C as simply competing with other public health concerns for resources, an alternative tack is to determine how the response to hepatitis C can be improved through improved links with other strategies, such as the National Drug Strategy. Use of the needle and syringe exchange program—originally developed as part of the National HIV/AIDS Strategy—to minimise hepatitis C transmission is a good example of using public health infrastructure in a broad, rather than disease-specific, way. Other efficiencies might well be realised through greater cross-strategy integration.

Although it is beyond the scope of this review to examine what priority hepatitis C should be accorded relative to other public health concerns, it is necessary to examine how important hepatitis C is as a concern and whether the current level of response is adequate. This will provide an indication of whether hepatitis C is accorded *sufficient* priority. The question of whether hepatitis C should be accorded *greater* priority is to be avoided since this implies the 'pecking order' approach.

11.2 The argument against doing more

It is possible to mount an argument to support the proposition that there is not a strong case for doing (much) more to deal with hepatitis C. The central elements of this argument are as follows.

- The importance of hepatitis C infection has been overstated. A proportion of people who become infected will clear the virus from their system without medical intervention. Many others will not progress to significant clinical symptoms and, for those who do, this may not occur for 20 years or more. It is possible that studies overestimate the number of people likely to progress to significant symptomatology because of the over-representation of medically acquired cases (where outcomes are worse) and people already in treatment.
- Hepatitis C does not pose a serious threat to the general community in the way that diseases such as HIV have done. The bridge to the general community—from injecting drug users, by sexual transmission—is very flimsy because of the inefficiency of this route of transmission.
- The high level of hepatitis C prevalence among injecting drug users means it will be necessary to greatly reduce the extent of unsafe injecting behaviour or the number or new injectors, or both, if we are to have a meaningful impact on the incidence rate. There are considerable challenges associated with greatly reducing unsafe injecting behaviour and limiting the number of new injectors: many injecting drug users do not see hepatitis C as a serious health threat; it is difficult to reach injecting drug users because of their geographic distribution, social behaviour, and the illicit nature of the injecting; and there is no identifiable, coherent community. Most researchers and others with an interest in the subject consider that the prevalence of injecting is increasing. And many are not convinced that the abstinence approach or the promotion of non-injectible routes of administration would significantly reduce the prevalence of injecting. The conclusion that could be reached is that enhancing prevention efforts may produce insufficient gain to justify the expenditure. In international terms, Australia has an extremely well developed infrastructure of education and prevention services designed to minimise blood-borne infections among injecting drug users. It is possible that the gains from an increased education and prevention effort would be marginal.
- There may not be enough entrants to the injecting drug user population to sustain current infection rates. The number of injecting drug users has been assumed to be increasing each year, with more new injectors than those who stop injecting, but it is possible this trend will not continue. If there is a reduction in the size of the at-risk population, saturation levels of infection would soon be reached. This would mean incidence would decline as the pool of at-risk people not infected decreased. The size and importance of the prevention task would thus be reduced.
- Advances in treatment may greatly increase the proportion of people for whom viral clearance can be achieved. Other treatment advances, such as antivirals, that are possible within the next five years may greatly improve the prognosis for infected people. Although prevention will remain better than cure, advances in treatment may lessen the consequences of hepatitis C infection.
- For many with an interest in the subject, the assessment of whether hepatitis C has been accorded sufficient priority is made by way of comparison with the priority accorded HIV. Internationally, HIV has been accorded unique priority and thus may not be the appropriate benchmark, particularly given some important differences between the two viruses.

- A cautious approach should be taken to estimates of hepatitis C prevalence and incidence. It could be argued that there is a wide bound of uncertainty about the projections' reliability, paralleling the earlier experience with HIV.

11.3 The argument for doing more

It is also possible to develop an argument that insufficient priority is currently being accorded hepatitis C. The central elements of this argument are as follows.

- Although there are particular difficulties associated with maximising safe behaviour among injecting drug users, the history of HIV education and prevention efforts demonstrates that change can be realised and sustained. There is no evidence to suggest that these gains cannot be extended by an enhanced effort.
- In many respects, Australia's response to hepatitis C is gaining pace, building on the foundations of earlier work. Although further gains in reducing incidence will be hard won, they are in some ways more likely given the benefits that will flow from the better coordinated response that is starting to emerge and that needs to be further developed. It is too soon to decide that it is 'all too hard': much more can be done.
- There are some indications that the incidence of hepatitis C may be declining, which may mean that education and prevention strategies are having an impact. If this is the case, it shows that it is possible to provide effective education and prevention interventions.
- Even with the possible decline in incidence, the number of new infections is still unacceptably high. The impact of hepatitis C infection on affected individuals will vary considerably and will not be of major consequence for some, but the very high incidence rate magnifies the public health importance of the problem. Education and prevention efforts need to be greatly enhanced to further reduce the rate of infection.
- Current estimates of hepatitis C incidence are largely based on the assumption that there is significant growth in the number of new injecting drug users each year. It would be dangerous to assume that, because the growth in the number of injecting drug users is not sustainable, incidence will decline. The reverse is possible, at least in the medium term, particularly in the current social and economic circumstances. If public health efforts to combat hepatitis C are not intensified this may mean implicit acceptance that large numbers of people will become infected.
- Even if the size of the pool of people at risk does start to decline as a result of a reduction in the number of new injectors, there are still large numbers of injecting drug users who have not yet been infected, despite the high prevalence rate. Since there is good evidence that the risk of infection increases the longer a person has been injecting, there would still be a need to prevent infections among current injecting drug users.

- Hepatitis C may pose a greater risk to the general community than is currently realised because of poor infection control in skin-penetration practices in non-health care settings.
- At least in the short term, advances in treatment will not have a major impact in reducing the public health importance of hepatitis C. This is because for many treatment will be neither attractive (institutional settings, increased side-effects) nor viable (compliance, access difficulties, treatment failures), and there may be high rates of re-infection among current injecting drug users.
- Failure to minimise the number of new infections will result in a costly burden for the health system in the years to come. Advances in treatment are likely to be expensive and to place considerable strain on already over-stretched hospitals. Prevention may be the most cost-effective option for dealing with the epidemic.
- Estimates of hepatitis C incidence and prevalence are reasonably reliable: there is a high degree of consistency between the estimates and other data sources. Knowledge of the epidemiology of hepatitis C is more advanced compared with the early knowledge of HIV epidemiology, so it is unlikely that the same degree of error in estimates will occur.
- Taking a stand on hepatitis C infection offers an opportunity to tackle the drug problem as a broad social problem. This would be in contrast with the current fragmentation between health, law enforcement and corrections. Society would benefit.
- Hepatitis C also offers an opportunity to develop a holistic, integrated approach to the range of primary health care problems associated with injecting drug users.

11.4 The relative merits of the arguments

It is obvious that the arguments for doing more, less or about the same in efforts to combat hepatitis C are complex. What is required is an assessment of the components of the respective cases and a weighing up of the overall strength of the argument. In some areas there is no or insufficient evidence to make an informed assessment—for example, what marginal gains in reducing hepatitis C transmission can be achieved through enhancing education and prevention programs, and at what cost? It is, however, not unusual for public health practitioners to lack important data on which to base their decisions. This can help to elucidate priorities but, given the number of new hepatitis C infections, it cannot be used as a basis to delay action. An assessment of options on the basis of the best available knowledge is often the only realistic course in the short term.

To some extent, the arguments presented in relation to the priority that should be accorded hepatitis C look at the question in isolation from the other benefits that would accrue, particularly for injecting drug users, from greater efforts to combat the virus. This could increase the cost-effectiveness of according hepatitis C greater priority.

In assessing the arguments it must be recognised that the hepatitis C epidemic is to a large extent being fuelled by the high and increasing number of injecting drug users. The best available evidence suggests that this trend will continue.

Undoubtedly there is merit in both the propositions discussed: doing more and not doing more. Rather than seeing the question polemically—that is, do nothing or do everything humanly possible—the question can be recast to ask whether Australia's current efforts in relation to hepatitis C are sufficient to meet the challenges posed by the epidemic. This has the advantage of avoiding the notion of a disease 'pecking order'. It also recognises that any determination of priority is a question of degree—that is, we need to think about what we must do to meet the challenges, rather than developing a comprehensive 'wish list' that may be unachievable.

Although there may be some merit in aspects of the thesis that there is not a strong case for doing a great deal more to redress the problem of hepatitis C, on balance the reviewers find the contrary argument stronger. Nonetheless, research, monitoring and evaluation are needed to guide the design of interventions and to measure their effectiveness.

11.5 Some impediments to according hepatitis C sufficient priority

There are three main impediments to according hepatitis C sufficient priority.

- It is a stigmatised disease, largely associated with injecting drug use. This factor is seen as limiting the public and political will to tackle the problem more effectively.
- A more conservative environment in relation to illicit drug use, coupled with community fear about drugs, has resulted in reluctance to extend the harm-minimisation approach.
- Hepatitis C is poorly understood by the general community. There is confusion about the different types of hepatitis and about routes of transmission, symptoms and the prognosis for the disease.

11.6 Strategies for according hepatitis C sufficient priority

Three main strategies may result in hepatitis C being accorded sufficient priority:

- presenting compelling data that spell out the prevalence and incidence of infection and the health care, social and welfare implications—this would strengthen the case of those advocating an enhanced approach;
- education of the general community, mainly about the disease itself and discrimination—this needs to include education in settings such as schools and tertiary institutions and workplaces at potential risk;
- placing hepatitis C in the context of the current debate on drug law reform and treatment options—this would help to expand the drug debate to take account of

broad social concerns, rather than perpetuate the current fragmentation between the law-enforcement, community services, health, corrections and other sectors.

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12 Challenges for the future

This chapter examines the five principal challenges that have emerged from the review's analysis of Australia's response to hepatitis C. In summary, the challenges are

- 1—reducing the number of new hepatitis C infections
- 2—improving treatment and care for people living with hepatitis C
- 3—'getting the research right'
- 4—extending partnerships
- 5—clarifying structures, roles and responsibilities.

For each challenge, relevant considerations are discussed, possible directions and priorities are outlined, and the essential components of an organised national response are delineated. The reviewers recommend that the suggested directions and priorities and the essential components of an organised national response be incorporated in a new strategic document that describes the action necessary to meet the challenges posed by hepatitis C. Chapter 13 discusses options for the overall model that might be used to fashion Australia's approach to the continuing epidemic.

12.1 Challenge 1—reducing the number of new hepatitis C infections

The most recent data on the incidence of hepatitis C infection in Australia are for 1997: it is estimated that in that year there were 11 000 new infections (with upper and lower limits of 8500 and 13 500). There is good evidence that the vast majority of new infections are occurring among injecting drug users. In the light of the very large number of new infections each year, a strong case can be made that the most fundamental and pressing challenge posed by hepatitis C is to reduce the number of new infections.

The infrastructure of standard prevention services for blood-borne viruses—needle and syringe exchanges, methadone programs, and education programs conducted by user groups—already existed by the time hepatitis C was recognised as a serious public health concern. The focus of all these services has expanded to accommodate hepatitis C and the output of some services, such as the needle and syringe exchanges, has been greatly expanded in all jurisdictions in recent years.

Increased funding for national community-based organisations—the Australian Intravenous League and the Australian Hepatitis C Council—could make the national education effort much more effective by allowing the creation of community-based infrastructure for the development and coordination of initiatives.

12.1.1 Matters for consideration

Hepatitis C's very high incidence rate is evidence that current education and prevention interventions are having insufficient impact. A number of matters warrant consideration: constraints on reducing the level of transmission; the situation in prisons; infection control in non-health care settings; the use of treatment and care services in secondary prevention; the effectiveness of current interventions; setting achievable targets; and the potential for vaccine development.

Constraints on reducing the number of new hepatitis C infections

There are a number of constraints on significantly reducing incidence. Hepatitis C infection was already well established among injecting drug users by the time the primary public health response—the needle and syringe exchange program and education for users—was implemented. Obviously, it is far more difficult to control an infectious disease once it has become well established.

Although there is evidence that most injecting drug users do not share needles on most injecting occasions, sharing still appears to occur more often than is desirable. People working in the area of injecting drug user education were of the view that breaches of aseptic technique are much more common than the sharing of needles and syringes, although the extent to which this leads to infection is not known.

The illicit nature of injecting drug use can work against the achievement of safe use. For example, some users may not have access to secure or private places in which to inject, making it more likely that breaches of aseptic technique will occur.

A combination of the high prevalence of hepatitis C among injecting drug users (60 to 70 per cent), the highly infectious nature of the virus, and occasional sharing or other unsafe injecting behaviour means that reducing the number of new infections is a formidable challenge. Because of these factors, the risk of infection per incident of sharing (or other unsafe injecting behaviour) is assumed to be quite high. As a consequence, even an occasional lapse in safe practice can expose people to a high risk of infection. It has been hypothesised—in the reviewers' opinion, correctly—that extremely high rates of safe behaviour would be needed on a sustained basis to significantly reduce the number of new infections. It is therefore reasonable to conclude that relying solely on an increase in safe injecting behaviour may not be sufficient to reduce the level of transmission to the extent necessary to produce results at a population level.

In spite of this, though, some reduction in the number of new infections may be possible if safe injecting practices become even more common. Research may provide answers about the efficacy of action to encourage this. But the difficulty of achieving a significant increase in safe injecting practice and the possibility that this would result in only marginal gains in reducing the level of transmission mean that it is useful to look for additional strategies designed to reduce transmission. A combination of strategies may be needed, since no single approach is likely to deliver sufficiently good results. Such a combination could include the following measures:

- increasing the level of safe injecting behaviour among current injecting drug users;

- decreasing the risk of infection—reducing the incidence of injecting drug use in the community by
 - reducing the uptake of illicit drug use, particularly injecting drug use,
 - decreasing the length of time injecting drug users continue to inject,
 - providing information about non-injecting routes of administration, particularly to people who have not begun injecting, and providing equipment that enables people to adopt this strategy.

Although some organisations already promote non-injecting routes of administration as one of a range of options for safer drug use, there has not been a major effort in this regard. Use of NIROA as a prevention strategy poses a number of difficulties. The idea is unlikely to be acceptable to current injecting drug users: a culture associated with the ritual of injecting has been established and non-injecting routes are a less efficient method of administration in terms of drug effect. As a result, this strategy is probably of relevance only to people who have not begun to inject. The problem with this is that reluctance to inject is seen as a barrier to the use of illicit drugs, or at least illicit drugs that are usually administered through injection, and provision of information about NIROA may remove this barrier, resulting in a greater number of drug users. Use of NIROA as a disease-prevention strategy for people who have not embarked on drug use may also be seen as pushing the boundaries of harm minimisation too far.

Although there are problems with NIROA-type messages, the very substantial difficulty of reducing hepatitis C transmission through reliance on increasing rates of safe injecting has led a small number of interested parties to call for consideration of the NIROA strategy. It has therefore been included as one element of a combination of strategies that could be used to help reduce the incidence of hepatitis C infection.

Just as there may be limitations to the efficacy of NIROA-type messages, some would see education strategies promoting abstinence from drug use as holding a slim chance of success. This may reflect the polarisation that has arisen out of the debate on the legal status of illicit drugs. There has been a tendency for the promotion of abstinence to be equated with 'zero tolerance' and this has led some to see abstinence as the antithesis of harm minimisation. An alternative view would be to see abstinence as one option among a range of harm-minimisation strategies. It may be time to consider whether greater emphasis needs to be given to the promotion of abstinence—not as the only course of action but as one of a range of alternatives within the harm-minimisation paradigm. From the perspective of hepatitis C prevention, the case for this rests largely on the proposition that as the number of injecting drug users increases so does the size of the pool of people at risk of infection.

Although surveys have shown strong community support for the needle and syringe exchange program there have been instances of community resistance, which have created political problems for the program in some jurisdictions. This may be a limiting factor in relation to further expansion of the program. In addition, more evidence is needed on the marginal gains in reducing new infections that might accrue if the program were to be expanded.

Given the high prevalence of hepatitis C among injectors, education messages need to target those already infected, as well as the non-infected, because unsafe practices by infected people are an important part of the equation in sustaining high incidence rates. The need for this is reinforced by the fact that people who are already infected can be re-infected with a different genotype, which may contribute to worse clinical outcomes. A number of people involved in the review process argued that education and prevention programs should place much greater emphasis on people who are already infected with hepatitis C.

Injecting drug users' attitudes to hepatitis C may act as a barrier to the acceptance of education and prevention messages. There appears to be a sense of fatalism among many injecting drug users: they assume they will end up becoming infected. Many do not see hepatitis C as a serious threat to their health because they perceive no impact on their lives or the lives of others. The possibility of illness is seen as many years distant, or other life needs may predominate.

Prisons

There is evidence to suggest that imprisonment is a significant risk factor for hepatitis C infection. This is because of the lack, or limited availability, of the means of prevention in prisons and the over-representation of injecting drug users in the prison population. The high turnover of prison populations also poses a threat to the wider community.

The extent of hepatitis C education programs for prisoners in the States and Territories appears to be highly variable. But prevention of infection in the prison environment may be an important factor in limiting the spread of hepatitis C in the general community, so there are good reasons for all jurisdictions to examine the adequacy of their education programs. Difficulties associated with providing prisoners with the means of prevention creates a particular challenge for reducing transmission in this population group. Nonetheless, a review of options in this area is important considering the role prisons probably play in incubating hepatitis C infection and the implications this has for subsequent spread to the general community.

Infection control in non-health care settings

The efficacy of infection-control procedures in non-health care settings where skin penetration occurs is unknown. The extent of inspection of premises by local government and the effectiveness with which this function is discharged would appear highly variable. Given the fairly widespread adoption of tattooing and body piercing in youth culture, skin penetration in non-health care settings is an area of concern.

Use of treatment and care services in secondary prevention

Treatment and care services may be able to play a secondary prevention role.

It is possible that simple contact between injecting drug users and the health care system in itself promotes safer behaviour. This can be enhanced where treatment and care services take the opportunity of contact to deliver education and prevention

messages. Interventions to help clients with life problems may also have the effect of reducing the risk of infection through creating a more stable lifestyle.

With improvements in hepatitis C treatment, a higher proportion of infected people will achieve viral clearance. This has led to discussion of whether treatment could become an important secondary prevention strategy. The rationale for such an approach is based on the assumption that the effect of treatment in reducing the pool of infected people would be great enough to substantially reduce the risk of infection through unsafe injecting behaviour. Although the merits of this approach should be kept under review, particularly as further treatment advances are realised, it would probably not be efficacious in the short term for the following reasons.

- Very large numbers of current injecting drug users would need to be enrolled in treatment programs to make a significant impact on the prevalence of infection. It is unlikely that this will be achieved, at least in the short term, because of factors relating to the acceptability of treatment and cultural and social barriers.
- There would need to be a high degree of compliance during the 12-month treatment period.
- For some injecting drug users the risk of re-infection would be high, thus defying the purpose of treatment.

The effectiveness of current interventions

As noted, the high incidence of hepatitis C is evidence that current education and prevention interventions are having insufficient impact. There are a number of possible explanations for this.

- There are problems with the design of interventions such as peer education.
- Injecting drug users most at risk of infection and people contemplating injecting drug use are not being adequately targeted. Part of the problem is that, with the exception of prisoners and data showing that the risk of infection increases with the length of time a person has been injecting, there is insufficient information to allow for a determination of which injecting drug users are most at risk. It is commonly assumed that, in addition to prisoners and new injecting drug users, other priorities should be young people, the homeless, and particular ethnic groups.
- It is possible the problem lies not so much with the design of interventions but more with whether the quantum of effort—especially the output and reach of standard prevention measures such as the needle and syringe exchange program, methadone programs, and user education—is sufficient for the size of the problem.
- The problem may lie with a combination of the design of interventions, their targeting, and the quantum of effort.
- Our understanding of the factors and behaviours leading to transmission of hepatitis C is incomplete.

- On the other hand, there are inherent difficulties in reducing the rate of hepatitis C infection, and it may be unrealistic to expect we can do much better than we are doing. In addition, too great an expenditure might be required for limited gain.

Research is needed to determine precisely where the problem of limited effectiveness lies—see Section 12.3.

Setting achievable targets

Consideration should be given to setting achievable targets for education and prevention. At present there is insufficient knowledge of the determinants of incidence to set meaningful outcome targets, such as a reduction in hepatitis C incidence to 5000 cases a year by the year 2001. In the medium term it will be possible only to define the basic service structure for reducing hepatitis C transmission and set targets in relation to outputs and intervention research. Section 12.1.3 lists the essential components of an organised national response designed to reduce the number of new hepatitis C infections. Section 12.1.2 proposes a process for setting targets.

Vaccine development

As detailed in Appendix C, there are considerable difficulties associated with the development of an effective vaccine for hepatitis C. Strategies aimed at reducing transmission of the virus will therefore need to be based on education and prevention for the foreseeable future.

12.1.2 Recommended directions and priorities

As noted, there is insufficient evidence to explain the limited effectiveness of current education and prevention interventions. This makes it difficult to determine what are the most appropriate strategies to reduce the number of new hepatitis C infections and to what extent this challenge can be met. Research to resolve this problem has been identified as a priority, but there will be a delay in obtaining results and, because of the difficulty of establishing cause and effect in social and behavioural research, the findings may be inconclusive.

The high hepatitis C incidence rate means there is an urgent need to develop more effective education and prevention interventions and that in the interim this will have to be done in the absence of research findings. Many of the possible strategies outlined in this section are based on the assumption that more effective education and prevention will be achieved by increasing the scope and output of current interventions. This is because it is difficult to propose changes to models without any research evidence on which to base proposals.

It is worth noting that the economic analyses conducted as part of this review (see Chapter 7) concluded that, although nothing is known about the marginal effectiveness of expanded investment in the needle and syringe exchange program, the magnitude of the beneficial effects already documented is such that it is highly unlikely that investment in the program has reached the point of negligible marginal returns.

As discussed, it is reasonable to conclude that, because of the difficulty of reducing hepatitis C transmission through sole reliance on increasing the extent of adherence to, and maintenance of, safe injecting practices, a multi-faceted approach should be adopted. This would involve development or enhancement of a variety of strategies to minimise the harm associated with drug use, ranging from abstinence to strategies that acknowledge and work with current injecting drug users. There are a number of possible strategies, as follows.

Reducing the prevalence of unsafe injecting

The prevalence of unsafe injecting may be reduced through further expansion of the needle and syringe exchange program to meet distribution targets based on injecting drug users always using sterile injecting equipment. Among the ways in which this could be achieved are the following:

- deregulation of the approval process for distribution of needles and syringes, so that sterile injecting equipment is available from a much wider range of outlets;
- the use of alternative distribution methods within the needle and syringe exchange program, such as vending machines, to maximise access, particularly out of hours;
- much greater use of mainstream outlets such as community health centres to expand geographic access;
- exploration of the appropriate balance between free and user-pays services;
- better support for needle and syringe outlets through improved staff training and resolving the problem of worker fatigue;
- exploration of options for providing preventive measures for prisoners.

Environmental factors such as the place in which injecting occurs are probably important in leading to unsafe practices, so provision of safe injecting places is another strategy that may have the effect of reducing hepatitis C transmission.

Another option would be to use a broader range of people—GPs, ambulance officers, other mainstream health care workers, police, and so on—to deliver 'safe using' messages to injecting drug users they come into contact with.

Reducing the prevalence of injecting

If the prevalence of injecting drug use is reduced the number of people at risk of infection will be reduced. Strategies in this regard fall into four broad groups.

- Reduce the uptake of illicit drugs, particularly injecting drug use. This could be achieved in two main ways:
 - more effective promotion of abstinence as one of a variety of harm-minimisation options;
 - responding to the full range of factors, including social factors, that contribute to the uptake of (injecting) drug use through an intersectoral approach to

matters such as youth unemployment and use of leisure time, homelessness, abuse, loss of identity and self-esteem, and support for sustaining change.

- Try to shorten the length of time that people inject. This could be achieved in four main ways:
 - active promotion of drug treatment options for injecting drug users early in their injecting careers;
 - increasing the range and availability of drug treatment options—including access to detoxification and methadone—sufficient to satisfy demand, and reorienting services to be ‘user friendly’ and to promote harm-reduction strategies;
 - expanding the role of the needle and syringe exchange program to include a range of other support services;
 - the introduction or expansion of methadone-maintenance programs in prisons.
- Make available information on non-injecting routes of administration as one of a variety of harm-minimisation options and provide equipment to allow people to opt for this strategy.
- Introduce diversionary sentencing, to reduce both the number of injecting drug users and the prevalence of hepatitis C in prisons, thus reducing the risk of transmission of the virus in this setting.

Enhanced education programs for injecting drug users

Enhancing education programs directed at injecting drug users may result in an increase in safe injecting or shortened injecting careers, or both. Possible actions fall into six broad groups:

- improved targeting of groups of injecting drug users known or believed to be at greater risk of hepatitis C infection—for example, prisoners, certain ethnic groups, young and new users, and marginalised users;
- increased emphasis on delivery of education and prevention messages to injecting drug users who are already infected;
- enhanced capacity of user organisations to provide peer education, support and advocacy for injecting drug users—greater support (not just financial) from State and Territory health departments is needed;
- development of a clear and consistent message on cleaning and re-use of injecting equipment, based on evidence of efficacy;
- education of injecting drug users about infection-control procedures;
- increased capacity of all health care workers to deliver education and prevention messages in their contact with injecting drug users.

Removal of the legal impediments to prevention

Laws that act as an impediment to the prevention of blood-borne infections among injecting drug users could be reformed. For this to occur, bipartisan support for harm minimisation needs to be re-established.

A clear process for consideration of the necessary legal reforms should be identified. This could occur through the appropriate sub-committee of the Australian National Council on AIDS and Related Diseases, in concert with legal matters being considered under the National Public Health Partnership.

Improving infection control

Infection-control procedures in health care settings and in the skin-penetration industry should be improved.

Setting achievable targets for education and prevention

The basic service structure needed to reduce the transmission of hepatitis C should be agreed on nationally—through the Intergovernmental Committee on AIDS and Related Diseases—and described in a document detailing Australia's response to hepatitis C. Section 12.1.3 lists the essential components of an organised national response to hepatitis C: this could be used as a basis for identifying the basic service structure.

In addition to a basic service structure, it is necessary to develop achievable targets for services. The Intergovernmental Committee on AIDS and Related Diseases, in close consultation with the Australian National Council on AIDS and Related Diseases, the Australian National Council on Drugs and the Intergovernmental Committee on Drugs should oversee work on this.

12.1.3 Essential components of an organised national response

1. Provision of sterile needles and syringes, sufficient to meet demand, so as to reduce the prevalence of unsafe injecting.
2. Education programs aimed at reducing the uptake of illicit drug use, particularly injecting drug use.
3. Provision of drug treatment programs such as methadone maintenance, sufficient to meet demand, so as to reduce the prevalence of unsafe injecting and the prevalence of illicit drug use.
4. Provision of safe injecting places to reduce the prevalence of unsafe injecting.
5. Education programs targeting injecting drug users through specialist agencies (such as peer-based programs developed and undertaken by user groups) and the use of mainstream health care workers, so as to reduce the prevalence of unsafe injecting and the prevalence of injecting.
6. Education programs and the provision of preventive measures in prisons.

7. Measures to reduce the number of injecting drug users in correctional centres through the adoption of cautioning systems for first offences and diversionary sentencing.
8. Removal of legal impediments to achieving a higher proportion of safer injecting amongst injecting drug users.
9. Establishment of an agreed basic service structure and realistic targets for education and prevention services.

12.2 Challenge 2—improving treatment and care for people with hepatitis C

12.2.1 Matters for consideration

Although all States and Territories have devoted additional resources to the treatment and care of people with hepatitis C, there remain a number of matters that warrant consideration: barriers to seeking testing; access to liver clinics; the capacity of primary care; access to care and treatment; advances in treatment; and support for hepatitis C–infected people.

Barriers to seeking testing

It is estimated that over 1.3 million tests for hepatitis C were conducted under the Medicare Benefits Schedule in the five years to June 1998. During this period there was an increase in the number of tests performed annually, to an estimated 340 000 in 1997–98. There are no data on the reasons for testing.

National surveys of injecting drug users attending needle and syringe exchanges, conducted by the National Centre in HIV Epidemiology and Clinical Research in 1995, 1996 and 1997, found a high and increasing proportion of users who reported having at some stage been tested for hepatitis C. In 1995, 77 per cent of those surveyed reported having at some time been tested; the figure increased to 80 per cent in 1996 and 84 per cent in 1997.

Nonetheless, if the estimates of prevalence are correct, a large number of people with hepatitis C have not been diagnosed. Possible reasons for this are a lack of awareness of risk (particularly for people who used to inject drugs but no longer do), alienation from the health system by marginalised at-risk people, the stigma associated with the virus, fear of a positive result, anxiety about confidentiality, and lack of symptoms. In the absence of a diagnosis, positive people cannot be assessed for treatment. As treatment advances lead to improved outcomes, this may become a more pressing concern. Testing can also be seen to have prevention implications, since people who receive a positive test result, particularly current injecting drug users, can be counselled on the need for safe behaviour.

At present there is no national policy on hepatitis C testing, although it is common practice in all jurisdictions for injecting drug users in contact with the health system to be offered testing.

Liver clinics

An infrastructure of treatment services has been established, and there are liver clinics in selected hospitals in each State and Territory. At present the only approved treatment is interferon, which is available only through liver clinics. The eligibility criteria for interferon treatment have recently been relaxed somewhat, although this is not expected to result in a large increase in the number of people in treatment in the short term.

Access to hospital-based liver clinics can be restricted by long waiting lists and the clinics' geographical distribution. It can be particularly problematic in regional and rural areas. The funding of clinical nurse consultant positions in some clinics has improved throughput, coordination of care, and the availability of information and counselling for patients, although access to counselling is reported to still be limited.

Only a small proportion of people with hepatitis C are current or previous patients of liver clinics. This is mainly a result of the very limited range of treatment options and quite tight clinical criteria relating to treatment eligibility. Although, as noted, the eligibility criteria are now less stringent, most hepatitis C-related care remains, appropriately, in the primary care sector. This will probably continue to be the case for the foreseeable future.

The capacity of primary care

There are a number of projects promoting the greater involvement of general practitioners in hepatitis C medicine but most of them are still in development or the early stages of implementation. Improving the capacity for a primary health care response offers the opportunity to take a more holistic approach to the needs of people with hepatitis C, in particular those with multiple health problems, which may be the case with many injecting drug users.

There are, however, limitations to the extent to which GPs may be willing to play a greater role in hepatitis C care. While most general practices may have a small number of patients diagnosed with hepatitis C, the number per practice is usually insufficient to warrant a big investment in hepatitis C-related continuing education. As might be expected, GPs generally prefer to develop their skills in areas that are more commonly represented among their patients. In addition, many GPs either do not wish to attract injecting drug users to their practice or do not have the skills needed for working effectively with these people. There are, however, a number of GPs with relatively large injecting drug user and hepatitis C caseloads and who have potential to further develop skills in hepatitis C medicine.

Among other outlets that may be appropriate for the delivery of primary health care to injecting drug users are youth agencies that have health clinics, sexual health centres, methadone clinics, outreach clinics at injecting drug users' organisations, and specialist

agencies such as the Kirketon Road Centre in Sydney's Kings Cross. The New South Wales demonstration projects may provide useful information in this regard.

In expanding the capacity of primary health care, it is important that the total health care needs of patients be taken into account. A good example of the limited perspective currently being adopted in relation to the primary health care needs of hepatitis C–positive people is the lack of attention to oral and dental care. South Australia provides an exception to this, though: a small pilot dental program to improve access and identify needs has been funded. There is some evidence that people with hepatitis C, and injecting drug users in particular, have poor dental health.

Another area where primary health care may contribute is in promoting health monitoring and maintenance for people with hepatitis C. This has been done extensively in HIV medicine. Hepatitis C councils and user groups are in a good position to promote this approach. For this to occur, however, links between liver clinics, general practitioners and community-based organisations need to be strengthened since hepatitis C councils and user groups can be a useful referral source.

Improving access to treatment and care

Improving access to treatment and care, especially for injecting drug users and people who do not live near current treatment centres, is also important. There are, however a number of difficulties associated with this:

- scepticism on the part of people with hepatitis C about the efficacy of treatments or concern about side-effects;
- distrust of the health system by many injecting drug users, particularly those who are most marginalised;
- some health care workers' negative attitudes towards people with hepatitis C, especially injecting drug users;
- some health care workers' poor knowledge of hepatitis C;
- asymptomatic people perhaps not accepting the need for monitoring and possibly treatment;
- possible poor compliance rates by some infected people with marginalised lifestyles;
- the potential benefits of treatment being lost if some infected people continue to engage in risk-taking behaviour and become re-infected.

Advances in treatment

There is good evidence that some important improvements in treatment will result from the introduction of high-dose induction therapy and combination treatment. Although the difficulties associated with improving access to treatment and care will limit the extent to which people with hepatitis C may benefit from treatment advances, there will probably be some increase in demand. It is essential to plan for an increase in demand for treatment, particularly given the existing pressures on liver clinics.

Other matters, such as the prompt assessment of the efficacy of new drugs in order to facilitate access and the role of polymerase chain reaction testing in clinical assessment, also demand attention. Genotyping could, in the future, be used to determine who best benefits from treatment with interferon and ribavirin.

Support for hepatitis C–infected people

Hepatitis C councils have been pivotal in providing emotional support and information for people with hepatitis C. This has included peer-based support groups, resource production, telephone information and support services, referral to other agencies, and inter-agency collaboration. The provision of such services should continue to be central to the councils' work.

12.2.2 Recommended directions and priorities

Improving access to treatment and care

Among the possible ways of improving access to treatment and care for people with hepatitis C are the following:

- enhancement of the capacity of liver clinics in hospital settings, sufficient to meet demand;
- provision of hepatitis C treatment through non-hospital health facilities to remove barriers to access, particularly for injecting drug users—examples are sexual health clinics, methadone clinics, medical services attached to youth agencies, Aboriginal medical services, and general practitioners;
- evaluation and promotion, as appropriate, of the New South Wales demonstration projects;
- making counselling more accessible.

Expanding the capacity of primary medical and dental care

Among the possible ways of expanding the capacity of primary medical and dental care are the following:

- coordination of education initiatives for GPs;
- over time, further development of the shared-care model to allow GPs affiliated with designated treatment centres to prescribe hepatitis C treatments as a way of preparing for the possibility of a larger population in treatment;
- incorporation of oral and dental health in a future national approach to hepatitis C, including removal of discrimination-related barriers to seeking and obtaining such treatment and care.

Promotion of health maintenance and monitoring

More emphasis on maintenance and monitoring is needed. The primary need is to meet the demand from people with hepatitis C for more information about treatment and lifestyle management, to encourage them to take responsibility for their health. This should include provision of information evaluating complementary therapies. Hepatitis C councils and user groups should be supported in this since their workers and supporters have the experience and expertise needed for developing the information and have ready access to the populations most in need of information.

Promotion of hepatitis A and hepatitis B vaccination for injecting drug users will reduce mortality and morbidity caused by dual infection and thus be an effective health-maintenance intervention.

Promotion of good clinical practice

Processes for assessing advances in clinical practice should be developed and, where appropriate, their incorporation in clinical practice in Australia should be promoted.

Health care workers need to be offered training designed to counteract stigmatisation of and discrimination against people who inject drugs and people with hepatitis C.

Data collection and health service planning

There are two priority areas for improving the estimation of the burden of hepatitis C-related illness in Australia:

- more information about the development of mid-term sequelae of hepatitis C infection—such as fatigue, depression and the inability to work—and the social and economic impact of these conditions;
- better data on the proportions of diagnosed liver cancer and cirrhosis associated with or as a result of hepatitis C infection.

Refinement of standardised data collection from treatment centres would increase our understanding of the results of various treatments and the natural history of hepatitis C infection.

In addition, projections of the quantity and type of future treatment and care interventions along with their resource implications are needed to inform the planning of State and Territory and regional health service delivery.

12.2.3 Essential components of an organised national response

1. Development of an agreed policy on hepatitis C testing.
2. Development and implementation of primary health care models, by general practitioners and public sector community clinics to deal with the health care needs of population groups with hepatitis C to ensure optimal access to counselling, testing and management

3. Enhancement of the capacity of liver clinics in hospital settings, sufficient to meet demand.
4. Access to the full range of treatment and care services for people who are imprisoned.
5. Established mechanisms for the continuing education of general practitioners and others who work in hepatitis C treatment and care and the incorporation in clinical practice of advances in care.
6. Provision of information and support, including health maintenance and monitoring, for people with hepatitis C through community organisations such as hepatitis C councils and user groups.

12.3 Challenge 3—‘getting the research right’

Hepatitis C research is funded from a number of different sources.

The competitive, investigator-initiated system administered by the National Health and Medical Research Council is one source. Applications are taken from a general pool; they are assessed on scientific merit, as judged by peer review, and must compete with applications from other subject areas. The NHMRC is considering whether hepatitis C should be granted ‘special initiative’ status, which would have the effect of increasing the number of hepatitis C research applications that are funded by reducing the cut-off score.

Under the Commonwealth AIDS Research Grants (CARG) scheme, project applications are assessed using procedures that are the same as those used by the NHMRC. Funds for hepatitis C research are available if the research is in an area where there is a clear and direct link with HIV/AIDS.

In addition, the Commonwealth Minister for Health has recently made a one-off allocation of \$1.7 million for hepatitis C research and national programs. The research component of these funds will be administered by the NHMRC, on the advice of the Australian National Council on AIDS and Related Diseases, and provide the opportunity to pursue research that will help guide the national response to hepatitis C.

Five national research centres—the National Centre in HIV Virology Research, the National Centre in HIV Epidemiology and Clinical Research, the National Centre in HIV Social Research, the National Drug and Alcohol Research Centre, and the National Centre for Research into the Prevention of Drug Abuse—are funded under the National HIV/AIDS Strategy and the National Drug Strategy. Although these centres have far wider briefs than simply hepatitis C, some hepatitis C research has been conducted in each one.

12.3.1 Matters for consideration

Our knowledge of hepatitis C has improved greatly in recent years, but the review has identified a number of areas for which research data are needed. If Australia can ‘get

the research right' and then apply the results, this will help in getting the response to the epidemic right. A number of matters warrant consideration: determining research priorities; recognition of the contribution of social research; the balance between investigator-initiated and directed research; the research–practice interrelationship; multi-disciplinary collaboration; the role of the national research centres; and community involvement.

Determining research priorities

Section 12.3.2 identifies some important research areas for which data are needed to guide Australia's response to hepatitis C. The list is not exhaustive. It concentrates on epidemiological and social and behavioural research, which can be used in measuring the impact of education and prevention interventions and in refining them.

There is a case for commissioning research into a limited number of areas that have the potential to provide answers in relation to aspects of the national response to hepatitis C. It is, however, outside the scope of this review to provide a detailed priority list for hepatitis C research. In any case, the ANCARD Hepatitis C Sub-committee, in consultation with the ANCARD Research Advisory Committee, is already involved in work to determine research priorities for hepatitis C.

It is important to consider what constitutes the 'best buys' for Australian research. In some areas we may be able to rely on the application of findings from international research. The 'best buy' approach would consider where Australia is uniquely placed to contribute to the development of knowledge about hepatitis C and what are the areas of research for which we will not be able to rely on the data of others—for example, context-specific research such as epidemiology and social research.

The contribution of social research

Social research has the potential to make a major contribution to containing the hepatitis C epidemic through findings that enable the refinement of education and prevention interventions. There is a strong perception among social scientists that research-funding mechanisms are biased in favour of biomedical research. If this is the case, special initiatives may be needed to foster hepatitis C-related social research since many of the areas where research is needed are concerned with the effectiveness of education and prevention interventions.

The balance between investigator-initiated and directed research

The right balance must be struck between research that is investigator initiated and strategic research designed to produce information that is needed for policy development or practice.

Strategic research can be investigator initiated or directed. It may be necessary to commission high-priority strategic research if the research is not being carried out through the investigator-initiated process. This could be done through ANCARD's Research Advisory Committee and Hepatitis C Sub-committee.

The research–practice interrelationship

Mechanisms that foster the research–practice interrelationship are needed. Such an interrelationship allows for two-way dialogue on research priorities and design and for findings to be incorporated in program design, refinement and implementation. The linking of hepatitis C research with the HIV/AIDS research program and the involvement of the national research centres would probably be useful in this regard.

Multi-disciplinary collaboration

A high degree of multi-disciplinary collaboration will result in a better understanding of interventions that are effective in lessening the impact of hepatitis C. Coordinating mechanisms and committee structures may be important in fostering this, and any barriers to collaboration should be removed. Nonetheless, niche or specialist research areas not capable of being approached in a multi-disciplinary way should be recognised.

The national research centres

There is a need to define the role of the national research centres funded out of National HIV/AIDS Strategy and National Drug Strategy funds in relation to hepatitis C research. At present centres funded under the HIV/AIDS Strategy are able to do hepatitis C–related research only if there is a clear and direct link with HIV/AIDS. There is also a perception that the centres funded under the National Drug Strategy are not being encouraged to undertake hepatitis C–related research. It is possible that the ‘related diseases’ approach is presenting an artificial barrier to the greater involvement of the national research centres.

In determining the nature and extent of the national research centres’ involvement, consideration should be given to the particular expertise each centre may be able to contribute.

Community involvement

The research effort should reflect the partnership approach through involving community members in setting priorities, in planning and conducting research, and in disseminating findings. The different perspectives brought by community members can add value through development of the research–practice interrelationship.

12.3.2 Recommended directions and priorities

Guiding principles

The research effort should be guided by the following principles:

- recognition of the contribution of social research, especially in relation to reducing the number of new hepatitis C infections;
- a balance between investigator-initiated and directed research;

- use and development of mechanisms to foster the research–practice interrelationship;
- encouragement of multi-disciplinary collaboration;
- community involvement in setting the research agenda, in the design and execution of research, and in disseminating results.

Determining research priorities

The Australian National Council on AIDS and Related Diseases has prepared a draft paper outlining research priorities relevant to hepatitis C, with a view to developing a three- to five-year research plan.

As part of developing research priorities, clear guidance needs to be given on the nature and extent of the national research centres' involvement in hepatitis C research.

In determining overall research priorities, consideration should be given to the following areas: surveillance; education and prevention; treatment and care; and clinical intervention.

Surveillance

There are four priority areas for research into surveillance of hepatitis C in Australia:

- improved estimates of the number of injecting drug users;
- the need for national sero-surveys to develop unbiased population estimates of hepatitis C prevalence;
- identification of groups of injecting drug users at particular risk of hepatitis C infection, to enable more refined targeting of education and prevention interventions;
- increased surveillance in priority settings such as prisons and among other high-risk groups, to better monitor the course of the epidemic and the effect of interventions.

Education and prevention

Research into the following areas has the potential to contribute greatly to the refinement of education and prevention interventions:

- the reasons for injecting drug users continuing to share injecting equipment and barriers to safe practice—this should include developing a better understanding of the context in which unsafe injecting takes place;
- whether a further reduction in the sharing of needles and syringes and improvements in other aspects of safe injecting, through focusing on the sterility of the injecting process, would produce a significant decline in hepatitis C transmission;
- a better understanding of the size of the injecting drug user population and its characteristics and dynamics;

- the reasons for choosing injecting over other routes of administration and possible incentives for and barriers to a change from injecting to other routes;
- evaluating the effectiveness of different preventive strategies, including their cost-effectiveness, so as to provide a guide to what are the 'best buys' for limited budgets.

Treatment and care

There are two priority areas for research related to treatment and care:

- identification of the barriers to seeking testing for people who are or have been at risk of infection;
- the development of service models that will improve injecting drug users' access to primary and secondary treatment, taking account of the full range of their health care needs.

Clinical intervention

There are four priority areas for research related to clinical intervention:

- virological and immunological studies of the determinants of hepatitis C clearance during primary infection;
- evaluation of the effectiveness of treatment as a prevention strategy;
- investigation of the relationship between predictors of disease progression and of response to treatment;
- evaluation of the efficacy of alternative therapies.

12.3.3 Essential components of an organised national response

1. Acceptance of a set of guiding principles.
2. Transparent processes for determining research priorities and funding the 'best buys' for Australian hepatitis C research.
3. A research plan that sets out priorities, mechanisms for funding, and the role of the national research centres funded under the National HIV/AIDS Strategy and the National Drug Strategy.
4. Processes for the commissioning of research to guide aspects of the national response to hepatitis C.
5. Recognition of the important role of social research in improving the design and delivery of interventions.
6. Adequate surveillance mechanisms.
7. Mechanisms for dialogue between social researchers and those involved in the design and delivery of education and prevention interventions, to allow for the

identification and refinement of research questions and the dissemination of findings and their translation into practice.

12.4 Challenge 4—extending partnerships

12.4.1 Matters for consideration

In relation to extending partnerships, three important matters warrant consideration: the restricted ownership of hepatitis C; the value of the partnership approach; and gaps in the partnership.

Restricted ownership of hepatitis C

The emergence of yet another serious public health threat, in the same general domain as HIV/AIDS, found strategists, policy makers and workers at the front line worn down by the prolonged struggle against HIV/AIDS. There is little community support for injecting drug users, who are the primary casualties of the hepatitis C epidemic. All this in a budgetary climate where new dollars are very hard to come by and accountability relationships between the Commonwealth and the States and Territories are changing through broadbanding and the new Public Health Outcome Funding Agreements.

Because the principal at-risk group was quickly identified, most of the prevention effort has gone directly to this group, bypassing the general community. As a consequence, important opportunities for broader community understanding of the problem have been lost. Another consequence is restricted ownership of hepatitis C, with only limited attempts having been made to extend and refresh the partnership links needed to bring new vigour to Australia's response.

The value of the partnership approach

The philosophy and practice of partnerships made a highly successful debut as a public health strategy in Australia's management of the HIV/AIDS epidemic. In the past decade a complex, and sometimes fragile, web has formed, linking political parties, governments at all levels, medical, scientific, research and health care professionals, community organisations, affected individuals and their families, friends and advocates, and communities. The involvement of affected communities in finding solutions and responses appropriate to them continues to be central to the partnership approach, chiefly because many of those affected are from marginalised groups traditionally suspicious of mainstream health and legal systems.

Australia's learning about the value of the partnership approach in HIV/AIDS stands it in good stead for refining its response to hepatitis C. Within the public health – infectious diseases fraternity, many of the partnerships that have already been formed can be of use—surveillance, laboratory testing, sexual health services, and so on. Social, scientific and drug use research structures exist, as do those for intergovernmental cooperation in public health.

Where are the partnership gaps?

A genuine partnership with affected people

In 'The Public Health Challenge of Hepatitis C', Neil Orr and Stephen Leeder argue that the partnership must include 'current and past drug users, those who are just beginning to inject and those who have left it far behind' (1998, p. 193). This is a large and disparate population whose members face problems associated with transmission, infection, re-infection, living with a chronic condition, and access to treatment and support. A large subset of this population also live with addiction, poverty, discrimination, and the constant threat of the law.

Critical to the success of the response to the HIV/AIDS epidemic has been the partnership status afforded the affected community. They have been brought into the various levels of policy and decision making, through genuine participation that goes beyond consultation. The broader aim of the partnership approach is to encourage ownership of the problem and engage affected communities in working responsibly with others to resolve it.

Many interested parties are adamant that much more needs to be done to strengthen the partnership between governments and the various communities affected by hepatitis C. What is required is a commitment to greater equity in the partnership with community organisations and their constituents, but this must be done sensitively, recognising their autonomy. On several occasions during the consultations for the review the need for more resources was raised, so that community organisations are better equipped to take a place at the table as truly equal partners and to be more representative of their constituents. This is the case for both user groups and hepatitis C councils.

There is potential to improve collaboration between user groups, hepatitis C councils, organisations targeting young people at risk, and haemophilia and transfusion-related groups through defining roles, functions and target populations and identifying common interests—see also Section 12.5. Mechanisms need to be developed and implemented at all levels to enable these groups to take a more prominent role in strategy development and decision making.

Recent funding of two national representative bodies—the Australian Intravenous League and the Australian Hepatitis Council—will allow for the development of some of the essential infrastructure to support partnership participation by affected communities. ANCARD's Hepatitis C Sub-committee contains representatives of the main affected communities, which, importantly, gives them partnership status at the national level. Much more remains to be done, though: the level of resourcing for user groups and hepatitis C councils varies greatly between States and Territories.

Extending the focus beyond current injecting drug users

Orr and Leeder make the point that 'the partnership must extend . . . into the wider community where past injecting drug users reside' (p. 193)—in other words, going well beyond current injecting drug users, reaching and mobilising a whole range of people who have been touched by or at risk of illicit drug use at some time in their lives and who may or may not have hepatitis C. This extended partnership, which should include parents as a major resource, has the potential to broaden the base of

skills, expertise and representation available to the national effort, de-stigmatise the disease, and provide a more stable base on which to build consultation and participation. It should also increase awareness of hepatitis C in the general community and, correspondingly, understanding of the disease and compassion for those affected by it.

Extending the medical response

Gastroenterologists have taken primary responsibility for the medical response to hepatitis C and an infrastructure of treatment services (liver clinics) exists in some hospitals. The rapidity of the gastroenterologists' response, and their preparedness to do what they can within available resources, has been commended.

As more is learnt about the affected population and the natural course of the disease, it is becoming increasingly clear that this initial response has perhaps been overly medical, especially in terms of its specialist and treatment orientation. The chronic, long-term nature of hepatitis C infection calls for active patient participation in its management, regular monitoring, and a holistic approach. A primary health care approach based on accessible general practice services is seen as the key to better meeting the needs of people living with hepatitis C, including injecting drug users.

This is an area where a much more active partnership is needed between the affected community and those providing treatment and care, to design models of care that are relevant to patients' actual needs. Development of communication between hepatitis C councils and liver clinics will help to extend the medical response.

Partnerships between specialists and general practitioners are also needed. Although effort has been put into shared-care models and GP education, much remains to be done to establish and build on a strong, comprehensive partnership between the two groups.

Effort also needs to be made to include sexual health services as one of the partners in the medical response. These services have good access to marginalised groups at risk of infection and expertise in the delivery of preventive and treatment-oriented services. They are already playing an important part, but they do not appear to be well linked to other health services, particularly hepatitis C specialists.

Given the expertise of infectious diseases physicians in dealing with communicable diseases, the question of the desirability of their greater involvement in treatment provision arises, particularly as antiviral treatments are increasingly used. Gastroenterologists will retain a primary role because hepatitis is a liver disease, but opportunities do exist for a closer partnership between these specialist areas.

Intersectoral partnerships

Hepatitis C is no respecter of bureaucratic boundaries. One of the successes of the response to HIV/AIDS lay in convincing other sectors that building their own internal capability to deal with HIV/AIDS was a sound long-term investment.

People in prisons, Indigenous Australians in high-risk locations, and young people at risk come variously under the auspices of corrections authorities, Aboriginal and Torres Strait Islander authorities, drug and alcohol authorities, community services,

and educational authorities. Although much has been achieved in some areas, efforts have been uneven. Most of these partnerships need to be built at the State and Territory level. The constant restructuring of government services and their management is an impediment to the long-term relationship-building on which these partnerships depend—patience, persistence and will are the cornerstone; additional funding can be invaluable.

Public health, drugs strategy and law reform

A serious threat identified in the consultations for this review is the fact that health concerns have not been given sufficient priority in the drug debate occurring in the public domain, tending to be overshadowed by law-enforcement and safety concerns. The intensity of community attitudes to drugs and crime has hindered a more open approach to the health-related problems of injecting drug users in particular. These people are stereotyped and feared, and there is little in the media to counter this.

Returning to the idea of extending the partnership focus beyond current injecting drug users, there is an urgent need to evoke greater community compassion for this population. Partnerships between governments, health authorities and the general community will lead to greater understanding of the problem and wider involvement in it.

In the long term, this should flow through to a more humane legal framework for responding to illicit drug taking and associated crime and a greater community will to tackle the social problems leading to drug use and to support the provision of a range of treatment and harm-minimisation options. This involves partnership between the health and justice systems, including the police.

Thus, the challenge presented by hepatitis C provides the opportunity for a unique partnership between those responsible for drugs strategy, public health, and law and order. The extraordinary complexity of the issues and the intensity of community feeling about them mean that it is easier for the various parties to confine their responses to their individual areas of responsibility. But this very complexity demands a complex, integrated, multi-faceted approach—which presents an enormous challenge to all concerned. This matter is discussed from a structural perspective in Section 12.5.

Political partnerships

The political will to bring about change is crucial if our response to hepatitis C is to be innovative, as it must be. The non-partisan momentum that supported a daring response to HIV/AIDS is considered by many to have waned, although at the national level the Parliamentary Liaison Committee still operates. The hepatitis C situation alone is not enough to stimulate the motivation required to generate some form of non-partisan support. But if health problems are set beside the problems our society faces with drugs, crime and the waste of lives, the reasons for a concerted, non-partisan approach to these problems become much more compelling.

The essential partnerships: a summary

The following list is not exhaustive but it does provide an indication of partnerships requiring development or consolidation:

- between governments (Commonwealth and State and Territory) and people with hepatitis C, including current and past injecting drug users, people just beginning to inject drugs, and people with medically acquired hepatitis C;
- between gastroenterologists and infectious diseases physicians, between these specialists, general practitioners and sexual health services, and between specialists, general practitioners and affected communities;
- between health and each of correctional services (adult and juvenile), community services, non-government organisations providing community services, Aboriginal and Torres Strait Islander services and their communities, and education authorities;
- between governments, affected people and the community at large, including parents;
- within whatever overall model is finally adopted, between the hepatitis C and alcohol and drugs strategies, at Commonwealth, State and Territory and community sector levels—at the strategy advisory, bureaucratic and community-based organisation levels;
- between health and the justice and policing systems, particularly in relation to law reform;
- between political alliances, energised through a multi-faceted approach to health-, drug- and crime-related problems affecting society at large—a non-partisan approach at the national and State and Territory levels.

12.4.2 Recommended directions and priorities

Commitment to the partnership approach

A commitment to extending the partnership approach will help in mobilising a broader range of participants in the response to hepatitis C.

Build the capacity of community organisations representing affected communities and extend the focus beyond current injecting drug users

Developing strategies to build the capacity of community organisations representing affected communities and extending the focus of the partnership beyond current injecting drug users may involve the following:

- ensuring that national and State and Territory user groups, hepatitis C councils, and organisations targeting young people at risk are properly equipped to play their part in expanding this aspect of the partnership and to be as representative as possible of their constituencies—this may entail a review of their respective roles, functions and resources and the development of some basic strategies;
- research to learn more about how the population of past injecting drug users might be reached and how they might be engaged in the partnership approach;

- reviewing and refining existing structures for participation of representatives of the affected communities in policy and decision making, at Commonwealth and State and Territory levels;
- reconsidering the role a public awareness campaign may have in achieving the goal of an extended partnership.

A primary health care approach

To extend the medical response to hepatitis C, further development work is needed to define the elements of a primary health care approach and how such an approach would be facilitated. This work should involve representatives of the affected communities and build on work already done through the Royal Australian College of General Practitioners, divisions of general practice, and State and Territory governments (for example, the New South Wales demonstration projects). A partnership between specialists, general practitioners and sexual health services, as foreshadowed in shared-care models, will be one outcome. Another will be a more viable partnership between the affected communities and their medical practitioners.

Build sustainable intersectoral partnerships

Initiatives to build sustainable intersectoral partnerships need to be part of the national and State and Territory strategies to reduce transmission of hepatitis C. The proposed national strategy document could provide a guiding framework (see Section 12.5).

Integrate efforts in public health, drugs strategy and law reform

A partnership is necessary to integrate efforts in public health, drugs strategy and law reform, initially in relation to the challenge posed by hepatitis C. A means of developing the partnership is proposed in Section 12.5.

12.4.3 Essential components of an organised national response

1. A partnership approach at all levels, with priority given to extending and supporting participation in the partnership by affected communities.
2. Structures and processes at national and State and Territory levels to encourage the contribution of all interested parties to policy and strategy development and decision making (see also Section 12.5).
3. User groups and hepatitis C councils appropriately resourced on a recurrent basis in each State and Territory.
4. Each State and Territory hepatitis C strategy having a component that deals with the need to build intersectoral partnerships.
5. Demonstrated effort (at national and State and Territory levels) towards building an integrated approach to the public health challenge presented by hepatitis C, involving drugs strategy and law reform. A non-partisan political approach to support these efforts.

12.5 Challenge 5—clarifying structures, roles and responsibilities

Clarifying structures, roles and responsibilities will assist in creating the environment to meet the challenges hepatitis C now poses for Australia.

The National Hepatitis C Action Plan outlines roles and responsibilities in relation to hepatitis C.

- The Commonwealth has a major role in the coordination and leadership of national health programs, with primary responsibility for the national hepatitis C testing strategy, national public education programs, research funded through the National Health and Medical Research Council, coordination of national surveillance, and approval and funding of pharmaceuticals.
- The States and Territories are responsible for policy direction and overall delivery of health services within their jurisdiction. They are also responsible for treatment and counselling services, education and prevention programs, public laboratory services, and the collection of surveillance data.

The Action Plan goes on to describe the roles and responsibilities of medical and health care professionals, professional colleges and associations, non-government organisations, and volunteers. Non-government organisations' role in advocacy and the development of policies and programs is mentioned.

The Australian National Council on AIDS and Related Diseases is responsible for advising the Commonwealth Minister for Health on how best to achieve national goals for the management, treatment, prevention and care associated with HIV and related diseases such as hepatitis C. ANCARD established its Hepatitis C Sub-committee to provide advice specific to hepatitis C. Most States and Territories also have advisory structures.

The Intergovernmental Committee on AIDS and Related Diseases provides a forum for regular Commonwealth–State liaison on policy, programs and activities relating to HIV/AIDS and related diseases, to ensure that these are coordinated.

The Australian Hepatitis Council, the Australian Intravenous League and the Haemophilia Foundation Australia are national bodies representing populations affected by hepatitis C.

The medical profession, particularly the Gastroenterology Society of Australia, has performed a longstanding and vital advocacy role for hepatitis C treatment and care services. More recently the Royal Australian College of General Practitioners and individual divisions of general practice have been active in the development and promotion of shared-care models.

12.5.1 Matters for consideration

In relation to clarifying structures, roles and responsibilities, a number of matters warrant consideration: implementation of a coordinated response; the Commonwealth's leadership role; hepatitis C councils; the National Public Health Partnership; and funding.

Implementation of a coordinated response

The National Hepatitis C Action Plan, developed in 1994, placed hepatitis C on the national agenda. Most jurisdictions developed their own strategies, consistent with the Action Plan. But no time frames or accountability measures were attached to the Plan, and the Australian Health Ministers Advisory Council agreed that no separately identifiable, national resources would be provided. Initially, there was no infrastructure to coordinate and oversee activities or to ensure that responsibility was assumed where appropriate. IGCARD now has this responsibility, and the establishment of ANCARD's Hepatitis C Sub-committee has provided an important focal point for hepatitis C expertise and advice nationally.

These are positive developments, but many people who were consulted during the course of the review claimed that, although structures and mechanisms exist, what has been lacking is a clear sense of direction and, most importantly, the will to make things happen. Lacking, too, has been the momentum usually associated with an effective national response.

The Commonwealth's leadership role

The review consultations revealed unanimous agreement on the need for national leadership and direction setting. Smaller jurisdictions in particular seek authoritative information on which to base their response to hepatitis C.

The dynamics of the Commonwealth's leadership role are complex, and indeed changing, especially in areas where States and Territories have primary responsibility for service delivery. Nevertheless, it is widely agreed that the Commonwealth is in a good position to bring parties together to deal with major problems. This is especially the case in areas such as hepatitis C, where there are obvious benefits to be gained from a coordinated, concerted national response, and is reflected in the establishment of the National Public Health Partnership.

The current national advisory structures—ANCARD and IGCARD—are considered effective within the existing model. Collaboration in and coordination of education and prevention activities across jurisdictions is promoted by the IGCARD Hepatitis C Education and Prevention Working Group. ANCARD's national leadership role in relation to hepatitis C has been assisted by the establishment of its Hepatitis C Sub-committee. But although incorporation of hepatitis C in the framework of the National HIV/AIDS Strategy has provided enhanced legitimacy this has not been accompanied by a delineation of hepatitis C-specific strategic pathways. There has been a lack of clarity about areas where hepatitis C can be effectively dealt with within the context of HIV/AIDS and areas where separate or additional initiatives are needed. The lack of resources available to the Hepatitis C Sub-committee has also been a problem. An up-

to-date strategy document that takes account of current needs and challenges is urgently needed.

Nevertheless, ANCARD has been responsible for a number of important initiatives, including securing \$1.7 million in funds for research and programs specific to hepatitis C and facilitating prisoners' access to interferon under the Highly Specialised Drugs Program.

Hepatitis C councils

The diversity of groups infected with hepatitis C poses a complex challenge to community organisations attempting to meet a range of needs. Where hepatitis C councils have been established, they appear to have provided an important avenue for people to obtain information about hepatitis C. An unstated role delineation has developed, whereby user groups primarily engage in education and prevention and hepatitis C councils primarily engage in care and support. There are, however, significant crossovers between both types of organisation.

The diversity of the needs of different target groups may well justify separate organisations, but this has tended to reinforce divisions between education and prevention and care and support, which can have the effect of limiting collaboration. In some jurisdictions relations between hepatitis C councils and user groups have been strained because of the delineation of roles, although the trend appears to be for this tension to dissipate, at least in most jurisdictions: the cross-representation of management committee members and the development of joint projects are evidence of this.

In view of the crucial role these organisations play as a point of contact with affected communities, further support for them in carrying out their respective roles is warranted.

The National Public Health Partnership

The National Public Health Partnership potentially provides an integrating mechanism for tackling problems such as hepatitis C that cross different national strategies. At present this is limited to providing an opportunity for the chairs of the various national strategies to meet and exchange information. It could be extended to a more formalised role and to help jurisdictions with methodologies for determining relative priority, for instance, based on principles such as return on investment.

The restructuring of the National Drug Strategy advisory committees to mirror those of the National HIV/AIDS Strategy should provide for more effective community involvement in the National Drug Strategy and closer collaboration in relation to communicable diseases.

The broadbanding of Commonwealth public health funding to the States and Territories offers jurisdictions the opportunity to provide additional funds for hepatitis C if they consider it to be a higher priority than other areas. There is an expectation that this will occur over time. Renegotiation of the Public Health Outcome

Funding Agreements in mid-1999 offers the opportunity to introduce outcome measures specifically relevant to hepatitis C.

Funding

If a more effective national response to hepatitis C is to be achieved, the question of sufficient resources cannot be avoided. Much has been achieved by using pre-existing non-hepatitis C programs and adapting them to meet hepatitis C needs. Good examples of this are the needle and syringe exchange program, methadone-maintenance programs, user groups' education of injecting drug users, and hospital liver clinics. The use of existing infrastructure has limited the amount of additional funds that have had to be allocated to hepatitis C.

It would, however, be unrealistic to expect the challenges discussed in this chapter to be met without additional funding by both the Commonwealth and the States and Territories. The limited availability of additional funds for hepatitis C has obviously been a significant constraint to a more effective response in all jurisdictions in relation to treatment and care and education and prevention.

The move away from dedicated Commonwealth–State funding programs for specific public health problems means that this traditional mechanism for confronting emerging public health problems no longer exists. The review's consultations revealed that more needs to be done to increase the general understanding of what the new mechanisms and opportunities might be.

Under the broadbanding approach, it is now the responsibility of each jurisdiction to determine the relative priority of public health concerns and provide funding accordingly. The National Public Health Partnership approach, however, offers an opportunity for a coordinated approach to according sufficient priority to emerging public health concerns. This may increase the possibility of better funding or lead to more effective use of existing allocations across all jurisdictions.

12.5.2 Recommended directions and priorities

Possible models for responding to hepatitis C are discussed in Chapter 13, although the reviewers make no recommendations relating to the detail of future advisory structures. Irrespective of the model eventually adopted, however, the following fundamental elements will be required.

National and State and Territory advisory and coordination structures

The current national advisory structures—ANCARD and IGCARD—are effective and their functions connected with hepatitis C need to continue. ANCARD's Hepatitis C Sub-committee has given impetus to the national effort, and the essential element to be retained (whatever the model) is a group of hepatitis C experts with a dedicated brief. Consideration may need to be given to whether everything possible is being done to facilitate participation by representatives of the affected communities—see Section 12.4. Advisory mechanisms at the State and Territory level are also essential to an organised national response to hepatitis C.

A new blueprint for a national response

Again, whatever model is adopted for the future, a new, up-to-date strategic document on hepatitis C is required, to provide a framework within which all jurisdictions, including the Commonwealth, can develop their more detailed responses by way of action plans for the triennium. Endorsed by Ministers responsible for health, the document should be a conceptual one that provides a blueprint for action. It should primarily be an authoritative guide to best practice in responding to the hepatitis C epidemic, giving guidance on the areas in which effort should be focused for greatest gain, based on the available evidence. At a minimum, the document should describe the following:

- roles and responsibilities;
- the strategic directions for meeting the challenges emerging from this review;
- a process for developing outcome areas and targets linked to those directions, agreed with the States and Territories, and incorporated in the Public Health Outcome Funding Agreements;
- the core service structure for responding to hepatitis C.

Such a document would be consistent with the focus on outcomes and targets, rather than dwelling on the detail of how these might be achieved. The detail would be covered in individual action plans, which would also designate resources.

Funding for an enhanced response

Although funds that could be used for hepatitis C come through the Public Health Outcome Funding Agreements, it will be necessary for each jurisdiction to determine how it might finance an enhanced response to hepatitis C. Additional funding can be obtained from one of four sources:

- re-allocation of public health funding from other areas that are of lesser priority;
- the allocation of additional funds from within the broader funds within the control of health departments (not just public health funds);
- the allocation of additional funds from treasuries, where increased current expenditure on prevention and treatment may be justifiable on the basis of future savings—a concept known as ‘measure and share’. The findings of the economic analysis will be important in this regard;
- the allocation of new funds linked to a specific set of hepatitis C initiatives.

The extent to which any of these options are taken up, if at all, will depend largely on decisions about relative priorities.

Monitoring mechanisms

Monitoring mechanisms, probably using existing structures, should be in operation at Commonwealth and State and Territory levels. Use could be made of the monitoring mechanisms established by IGCARD and the National Drug Strategy, which should be

informed by the work of the National Public Health Partnership Planning and Practice Working Party. Each jurisdiction, including the Commonwealth, would need to monitor implementation against its action plan, as well as monitoring progress towards outcomes and targets. At the national level, however, the focus of monitoring would be twofold: reviewing progress towards outcomes and targets; and supporting the partnership by identifying and overcoming obstacles.

Linkage with the National Drug Strategy

Words such as 'linkage' are often used to describe the need for programs or services to be connected and work together. But 'linkage' suggests passivity: something much more active is needed in this case. Integration is a challenge that, like any other challenge, requires commitment, planning, agreed outcomes and, importantly, accountability.

The National Public Health Partnership aims to strengthen the basis on which national strategies can be developed and implemented through improved communication and collaboration across existing strategies and emerging strategies and the identification of best-practice models in national strategy development and implementation.

The National Strategies Coordination Working Group has been established to assist in this regard. Its draft paper, 'Work in Progress: paper on national strategies coordination', contains suggestions for working on coordination. Regular meetings of the chairs of the various national strategy committees have also been initiated.

The National Public Health Partnership could consider some additional initiatives in promoting integration across national strategies. The most important link from the hepatitis C perspective is with the National Drug Strategy. An integration working party with representatives from both strategy areas could be established to identify areas for increased collaboration and consistency, so that initiatives enhance and support one another. This may need to be reflected at the State and Territory level.

One way of thinking about collaboration might be in terms of the principal points of intersection between the two strategy areas, where a more coordinated approach could be of mutual benefit. For instance, in relating to the principal community at risk—current and prospective injecting drug users—both strategy areas will have programs, activities and messages that should be aligned. The same applies to the general community—including parents and schools—on the range of appropriate responses to drug use. Because hepatitis C has been managed within the context of AIDS and related diseases, the response to hepatitis C has evolved as a disease-management concern rather than a drug use one. Hepatitis C can be viewed through either 'window'—disease or drug use—but the reality is that an integrated approach is needed, where communicable diseases are seen as central to the Drug Strategy, not peripheral to it.

Further support for community-based organisations

Support for community-based organisations is discussed in Section 12.4, where note is made of the variable level of support provided to such organisations representing the affected populations. Additional support does appear to be needed, to enhance the

capacity of user organisations and hepatitis C councils to do their work with increased reach and without duplication. This is especially important for organisations representing injecting drug users, given users' potential for marginalisation. The nature of that support would be determined in close consultation with the organisations concerned.

12.5.3 Essential components of an organised national response

1. Advisory and coordinating mechanisms at national and State and Territory levels with the capacity for a dedicated approach to hepatitis C.
2. A new strategic document on hepatitis C that provides a framework for the development of more detailed action plans by the States and Territories and the Commonwealth.
3. National mechanisms for monitoring progress against outcomes and overcoming obstacles to achieving those outcomes. State and Territory mechanisms for monitoring implementation and progress towards outcomes. These mechanisms would be existing structures.
4. User groups and hepatitis C councils appropriately resourced on a recurrent basis in each State and Territory—see Section 12.4.
5. Adequate funding to support activities that arise from the strategic approach.
6. Inclusion of hepatitis C outcomes in Public Health Outcome Funding Agreements between the Commonwealth and the States and Territories.
7. The National Public Health Partnership to extend its leadership role in promoting integration across national strategies by establishing an integration working party with representatives of both the hepatitis C and drug strategy areas. The working party should identify areas for increased collaboration and consistency, so that the strategies enhance and support one another. This commitment to integration should be reflected through formal mechanisms at the State and Territory level.

References

Orr, N & Leeder, S 1998, 'The Public Health Challenge of Hepatitis C', *Australian and New Zealand Journal of Public Health*, vol. 22, no. 1, pp. 191–5.

13 Models for a strategic response

The National Hepatitis C Action Plan was developed in 1994. It laid the foundation for the national response to hepatitis C and most of its recommendations have been implemented. Although many of the strategic directions outlined in the Plan remain relevant today, the Plan is in other respects now dated. It has since been supplemented by the incorporation of hepatitis C in the National HIV/AIDS Strategy 1996–97 to 1998–99—where there are clear and direct links with HIV/AIDS. This has significantly boosted the national response by giving hepatitis C increased legitimacy in terms of public health. Nonetheless, the National HIV/AIDS Strategy does not set out strategic pathways for hepatitis C. As a result—and considering the waning relevance of the National Hepatitis C Action Plan and the lack of specific direction in the National HIV/AIDS Strategy—the national response to hepatitis C is occurring in the absence of a document that describes a clear and coherent approach to tackling the challenges now posed by the epidemic.

There appears to be consensus among interested parties that the situation should be remedied by the development of a revised approach that will give momentum to Australia's response to this important public health concern.

This chapter discusses three possible models for a more coherent approach to hepatitis C and the criteria with which to assess the suitability of each model. The models range from taking a disease-specific approach to integrating hepatitis C strategies with those relating to other communicable diseases.

It is important to note that what is being discussed here is the best way of organising the national strategic approach to hepatitis C. Although each of the models has important implications for how Australia responds to hepatitis C, some aspects of the way we respond will not be affected by which model is ultimately used.

- Dedicated funding would not be tied to any of the models. Commonwealth public health funding has now been broadbanded and none of the models has the capacity to change this. Whichever model is used, the strategy document would set out the broad approach: the level of funding would be a matter for each jurisdiction to decide.
- The States and Territories would not be bound to replicate the national model. Current State and Territory responses range from dedicated hepatitis C strategies to incorporation of hepatitis C in a sexual health and blood-borne diseases strategy, in contrast to the current national HIV/AIDS and related diseases approach.
- If the Commonwealth chose to integrate the response to hepatitis C with the response to other communicable diseases this would not necessarily have implications for community organisations. The functions of independent community-based organisations would not need to be integrated since this should be determined by local decisions about how best to deliver services.

13.1 The disease framework and its relationship to the National Drug Strategy

Historically, the Australian response to hepatitis C has been constructed using a disease framework. This is reflected in the National Action Plan, where the response is framed in relation to the causative viral agent. This approach has been continued by the incorporation of hepatitis C in the National HIV/AIDS Strategy. The reason for using a disease framework lies in the similarities between hepatitis C and HIV in terms of response. Two of the most important initiatives for preventing hepatitis C—needle and syringe supply programs and education on blood-borne diseases for injecting drug users—were initiated and funded under the National HIV/AIDS Strategy. It is therefore not surprising that a disease focus was used to develop the national response to hepatitis C.

The future control of hepatitis C in Australia will depend on the success of strategies designed to prevent transmission occurring through injecting drug use. Accordingly, matters related to injecting drug use that come within the framework of the National Drug Strategy will be of vital importance to the success or otherwise of Australia's response to hepatitis C. It is essential that links between disease-related strategies to deal with hepatitis C and the National Drug Strategy be improved, with the aim of achieving a high degree of integration. This is discussed in Section 12.5.

13.2 The models

One of the following three models could be adopted for continuing Australia's response to hepatitis C: separate hepatitis C and HIV/AIDS strategies; further development of the HIV/AIDS and related diseases approach; or a communicable diseases framework with specific sub-strategies.

13.2.1 Model 1—separate hepatitis C and HIV/AIDS strategies

If separate hepatitis C and HIV/AIDS strategies were pursued abandonment of the AIDS and related diseases approach would be the result. There would be two separate, disease-specific strategies that fully describe the approach to be taken to the particular challenges of each disease. In essence, the rationale for this model is that the strategic approaches required by hepatitis C and HIV are so different that separate strategies and structures are necessary. But there are also areas of clear and direct linkage between hepatitis C and HIV, particularly in relation to programs targeting injecting drug users, so mechanisms for the coordination of each strategy and separate advisory and implementation structures would still be necessary. Coordination with other relevant public health strategies would be necessary too, the National Drug Strategy being of particular importance.

13.2.2 Model 2—further development of the HIV/AIDS and related diseases approach

In further developing the HIV/AIDS and related diseases approach, the strategy would set out clear directions in relation to hepatitis C as well as HIV/AIDS. This approach differs from the current HIV/AIDS and related diseases approach, which is largely confined to HIV/AIDS-specific strategies. There would also be capacity to incorporate sub-strategies, or strands, relating to other areas such as sexually transmissible diseases and Indigenous Australians' health. An alternative, still using this overall framework, would be to have sub-strategies, or strands, built around population groups rather than diseases. Among the population groups could be homosexually active men, injecting drug users, Indigenous communities, sex workers, prisoners, and the general population. The primary rationale for a continuation of the related diseases approach is that there are clear and direct links between hepatitis C, HIV and other related diseases, and benefits arise from an integrated approach.

An option would be to rename the strategy to reflect the integration of hepatitis C-specific strategies with HIV-specific strategies—the National HIV/AIDS and Hepatitis C Strategy. This may help to allay the concern raised frequently during consultations that describing hepatitis C as a 'related disease' implies a lower priority for either HIV/AIDS or hepatitis C. Nevertheless, having a more inclusive title should not be taken to suggest equal priority: decisions about relative priorities should be made using clearly enunciated criteria and transparent processes.

13.2.3 Model 3—a communicable diseases framework with specific sub-strategies

A broad communicable disease framework would be developed to guide the national response to all communicable diseases of public health significance. The framework would include the following:

- clearly stated overall goals and objectives;
- principles to guide the philosophy and approach;
- broadly delineated roles and responsibilities¹;
- nationally coordinated surveillance systems;
- monitoring and evaluation mechanisms;
- strategies for training and workforce development;
- strategies for promoting research and linking findings to policy and practice;
- advisory and consultative mechanisms;
- structures for intrasectoral and intersectoral collaboration.

Since specific strategies need to be adopted for different types of communicable diseases or population groups at potential risk for particular diseases, the framework would also need to contain separate strands, or sub-strategies. These could be built

¹ This would not preclude more specific roles and responsibilities being delineated in relation to sub-strategies for specific diseases.

around particular communicable diseases, groups of similar diseases or population groups, as appropriate. The disease groups could be blood-borne viruses, sexually transmissible diseases, food-borne diseases, vaccine-preventable diseases, diseases spread by casual contact, and so on. The population groups could be Indigenous Australians, injecting drug users, homosexually active men, young people, the general community, particular ethnic groups, and so on.

These separate strands, or sub-strategies, would fully describe the approach to be taken to particular diseases. If the framework grouped diseases into particular categories, such as blood-borne diseases, it would be necessary to differentiate between strategies that applied to all blood-borne diseases and those that applied only to particular blood-borne diseases. This would obviate the problem of the current HIV/AIDS and related diseases approach in relation to hepatitis C, where strategies for meeting the challenges particular to this disease are not described.

Under this model there would probably be an overall policy advisory committee and an expansion of the function of the Intergovernmental Committee on AIDS and Related Diseases to cover all communicable diseases. In addition, a strong case can be made for a sub-level of advisory committees to more specifically deal with particular diseases, or groups of diseases, to ensure that the focus on particular challenges is not lost and that interested parties continue to be involved.

Mechanisms for coordination with other public health initiatives that have a focus broader than communicable diseases, such as the National Drug Strategy, would also be needed.

13.3 Criteria for assessing the models

A number of criteria for assessing the three models can be used: the extent of coordination the model offers; the ability to respond to the challenges presented by hepatitis C and HIV; sensitivity to population groups and their needs; efficiency; transparency in priority setting; flexibility; sustainability; and consistency with policy directions in public health.

13.3.1 Coordination

The lack of coordination between a number of strategies at the national and State and Territory levels has long been seen as a serious limitation. It can lead to overlap between programs, even contradictory initiatives. The separate development of programs can also result in inadequate consideration of the range of different perspectives on particular matters.

Coordination of the strategic approach to different diseases can enhance program efficiency and outcomes. It is essential where there are clear and direct links, as is the case with hepatitis C and HIV, particularly in relation to injecting drug use.

The more integrated approach outlined in models 2 and 3 is more likely to result in effective coordination than the disease-specific approach of model 1. For example, if

there were separate hepatitis C and HIV strategies it would unnecessarily complicate the important area of coordination with the National Drug Strategy in relation to injecting drug use and communicable diseases.

13.3.2 How best to respond to the challenges posed by hepatitis C and HIV

Perhaps the greatest danger of a more integrated approach is that problems particular to one disease or community can disappear from view in the bigger picture. An effective response may rely on the design of quite specific interventions to deal with particular problems. To a large extent this is the difficulty with the current AIDS and related diseases approach: the National HIV/AIDS Strategy does not identify specific hepatitis C strategies and this has given rise to the perception that hepatitis C concerns have not been accorded sufficient prominence. This situation can be overcome if an integrated strategic response allows for the clear expression of strategies specific to a particular disease. Models 2 and 3 allow for this.

It could be argued that the existence of a separate strategy (model 1) may result in hepatitis C being accorded greater symbolic prominence. This is not necessarily the case, though: such an argument probably reflects the notion that, for many, a specific strategy is seen as the equivalent of a dedicated funding program. This is no longer the case and decisions about relative priorities for funding will be made separately. Indeed, it could be argued that by separating hepatitis C from other communicable diseases of public health importance, hepatitis C could be perceived to have lower priority.

The desirability of integration can also be assessed by considering the extent to which hepatitis C and HIV have common needs. In some areas there are very strong, clear and direct links between the two diseases. This particularly applies to education and prevention programs targeting injecting drug users. There may also be some crossover in the area of social research and surveillance. There is, however, an absence of substantial links in other areas, such as prevention programs targeting homosexually active men and treatment and care, but this should not be seen as an impediment to a more integrated approach. Integration should not be interpreted to mean that all needs are identical and will be responded to in the same way.

The existence of clear and direct links between some aspects of hepatitis C and HIV should also not be interpreted to mean that identical strategies will suffice. For example, on the basis of what is known about the incidence and prevalence of HIV and hepatitis C it is reasonable to conclude that programs aimed at injecting drug users are successfully containing the spread of HIV but not hepatitis C. It would appear that some additional measures may be needed to significantly reduce the rate of hepatitis C infection. This highlights the need for any integrated approach to carefully assess the strategic response required to particular diseases, rather than assume complete commonality.

13.3.3 Sensitivity to population groups and their needs

An essential element of any successful strategy is the full involvement of affected communities to ensure the strategy's relevance and sustainability. The involvement of gay community organisations in the development and management of the National HIV/AIDS Strategy has been essential to ensuring the vitality and effectiveness of that initiative. A possible drawback of an integrated strategic approach to all communicable diseases is that community organisations could be marginalised. This would be particularly the case if national advisory committees became generic in nature: the voice of the community would become faint. It is possible that a more medical or public health technocratic approach could become dominant, although this might be avoided by the establishment of advisory structures (within the communicable diseases framework) similar to those that now exist for HIV/AIDS and hepatitis C but specific to particular diseases or groups of diseases.

Any strategy that ignores the health and social needs of injecting drug users will be limited in effectiveness. Specific attention to these needs is more likely to be achieved by a disease-specific approach, but it is also possible with the integrated approaches of models 2 and 3, provided the strategy builds in the capacity for the full involvement of representatives of affected groups and takes account of their concerns.

13.3.4 Efficiency

One possible advantage of a more integrated approach is the realisation of greater efficiencies through optimising the use of expertise across diseases, where relevant and beneficial, and the streamlining of infrastructure development in areas such as surveillance, monitoring and evaluation. Integration would also encourage the adoption of best practice in relation to a range of communicable diseases. Model 3 would streamline the management of communicable diseases.

13.3.5 Transparency in priority setting

A greater level of integration will result in greater transparency in decisions about the relative priority to be accorded particular diseases. Questions relating to priorities are more likely to be resolved if all communicable diseases are dealt with through one overall framework.

13.3.6 Flexibility

A single-disease focus offers less flexibility than an integrated approach because a single-disease approach leads to rigidities and boundaries between programs. An important advantage of model 3 is that it provides a broad framework for responding to emerging problems connected with communicable diseases without there being a need to develop a dedicated infrastructure each time a new threat emerges. If a framework for monitoring, anticipating and responding to communicable diseases in a general and continuing way is established the result is a shared foundation that enables a tailored response to individual diseases.

13.3.7 Sustainability

It is important that the chosen model be sustainable over time. In general, integration will probably increase the likelihood of maintaining a strategic response because collaborative relationships will enhance the capacity to produce results in the longer term.

13.3.8 Consistency with policy directions in public health

In Australia thus far the emphasis has been less on developing a cohesive public health system and more on establishing separate, problem-specific public health strategies. Public health effort needs to be drawn together into a more integrated system that has the capacity to act on established problems and to anticipate and respond to emerging ones. The development of the National Public Health Partnership is a response to this.

To revert to a single-disease focus would be to take a direction that is contrary to the way in which public health infrastructure is developing. On the other hand, adoption of model 2 or model 3 would assist in building broader public health partnerships.

13.4 Conclusion

One of the principal findings of this review concerns the need for additional momentum in the national response to hepatitis C through the clear enunciation of strategies for action in the identified challenge areas. The central question is whether this should be done by developing a dedicated hepatitis C strategy or by promoting an integrated approach to the whole problem of communicable diseases.

Single-focus national strategies have had considerable success in the past. As a consequence, such an approach continues to attract support in some quarters. But the fundamental limitation of this approach is that strategies have developed in isolation from each other, in the absence of a holistic approach to the health of the population groups concerned.

The value of a more integrated, coordinated and collaborative approach lies in efficiency, transparency, flexibility, sustainability, and consistency with current directions in public health.

The challenge associated with developing and implementing a more integrated approach involves maintaining support for the priorities of existing strategies while at the same time managing coordination in a way that enhances the capacity for cooperation. If care is taken to construct an integrated approach in a way that recognises the need for disease-specific approaches to certain aspects of the response, integration will not result in the loss of focus associated with single-focus programs. The reviewers recommend consideration of either model 2 or model 3.

The development of a communicable diseases framework, as outlined for model 3, would probably take time. The danger is that effort put into developing the framework could, in the short term, distract attention from formulating a more effective national response to hepatitis C. One option would be to take a staged approach to the

development of the framework. This would see some effort go into developing at least the basis of the overall framework—principles, surveillance mechanisms, and so on—and the strands, or sub-strategies, relating to hepatitis C, HIV and other related diseases. The development of strands for other communicable diseases could follow. Another possibility is the adoption of model 2, with the intention of working towards a communicable diseases framework.

A clear majority of those who attended a national mid-review consultation workshop favoured a communicable diseases framework with the capacity to deal with hepatitis C and other diseases as specific sub-strategies. Participants acknowledged, however, that the development of such a framework may take time and that this should be worked towards progressively.

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Appendixes

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Appendix A Submissions, interviews and workshops

Submissions

Submissions were sought via a national advertisement in the media and by direct invitation to specific individuals and organisations. Relevant government departments and organisations were also asked to complete a survey on the implementation of the recommendations in the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach

Submissions were received from the following people and organisations:

Patricia McLoughlin
Centre for Education and Information on Drugs and Alcohol
New South Wales

Anne Edwards
Australian Nursing Federation
South Australian branch

Elizabeth Dax
National Serology Reference Laboratory Australia
Victoria

Donna Taylor
Haemophilia Foundation Victoria

Steven Hall
National Hepatitis C Education Program for General Practitioners
Royal Australian College of General Practitioners

Wendy Loxley
National Centre for Research into the Prevention of Drug Abuse
Curtin University of Technology
Western Australia

Margaret Hamilton
Turning Point Alcohol and Drug Centre
Victoria

Justin Rowe
Past President of the Hepatitis C Council of Victoria and Victorian Hepatitis C Educator and Counsellor from 1995 to 1998

Anne Fletcher
Silver Chain Nursing Association
Western Australia

Peter J Farrell
South Australia

Kate Dolan
National Drug and Alcohol Research Centre
University of New South Wales

Justin Hoffmann
Haemophilia Foundation South Australia

Robert Batey
Department of Gastroenterology
John Hunter Hospital
New South Wales

Susan Kippax
National Centre in HIV Social Research
School of Behavioural Sciences
Macquarie University
New South Wales

Tim Gresham
Abbott Diagnostics Division
New South Wales

Australian Federation of AIDS Organisations

Australasian Society for HIV Medicine Inc.

Alcohol and Other Drugs Council of Australia

Submissions and surveys were received from the following officers representing government departments:

Mark Jacobs Director, Environment and Public Health Branch Tasmanian Department of Community and Health Services	Australian Capital Territory Department of Health and Community Care
John Carnie Manager, Infectious Diseases Unit Victorian Department of Human Services	Leo Keliher Commissioner New South Wales Department of Corrective Services
Jim Dadds Director, Resources and Planning, Public and Environmental Health Services South Australian Health Commission	John Paget Chief Executive South Australian Department for Correctional Services
Jan Savage Coordinator, AIDS/STD Unit Disease Control Centre Northern Territory Health Services	Tony Falconer Health and Medical Queensland Corrective Services Commission
Ross O'Donoghue Director, AIDS and Infectious Diseases Branch New South Wales Department of Health	James Ryan Australian Capital Territory Corrective Services Australian Capital Territory Attorney-General's Department
Linda Selvey Director, Communicable Diseases Queensland Department of Health	Cathy Mead National Centre for Disease Control Population Health Division Commonwealth Department of Health and Aged Care
Lewis Marshall Medical Coordinator of the Communicable Sexual Health Program Health Department of Western Australia	Roger Hughes Manager Drug Strategy Public Health Social Marketing Branch Population Health Division Department of Health and Aged Care
Simon Rosenberg Manager, Health Strategies Development Unit	

Submissions and surveys were received from the following non government organisations and committees or their representatives:

Australian Council on Aids and Related Diseases (Australian National Council on AIDS and Related Diseases Hepatitis C Sub-committee)	Tamara Speed Western Australia Substance User Association (Inc.)
Jennifer Ross Haemophilia Foundation Australia	Haematology Day Centre Royal Adelaide Hospital
Linda Bromley Hepatitis C Council Western Australia (Inc.)	One unnamed

People interviewed

Interviews on the challenges facing the management of hepatitis C were held with the following people:

South Australia

Geoff Higgins
Institute of Medical and Veterinary Science

Russell Waddell
Clinic Manager
STD Control Branch
South Australian Health Commission

Kirsty Hammet
HIV Programs Unit
South Australian Health Commission

Kim Petersen Manager HIV Programs Unit
South Australian Health Commission

Elizabeth Coates
South Australian Dental Service

Doreen Rae
Health Project Officer
Offender Services
Department of Correctional Services

Alan Yale
Adelaide Counselling Team

Colin Harris,
Hepatitis C Council of South Australia

Darren Mounkley
Gastroenterologist
Noarlunga Medical Centre

David Shaw
Head, Infectious Disease Unit
Royal Adelaide Hospital

Sue Tossel
Infectious Disease Unit
Royal Adelaide Hospital

Peter Jarratt
Environmental Health Branch
South Australian Health Commission

Gary Clarke
SAVIVE
AIDS Council of Australia

Bob Braithwaite
AIDS/HIV Program, Drug and Alcohol Services
Council of South Australia

Anne Hayes
Communicable Disease Program
Drug and Alcohol Services Council of South
Australia

Judith Cross
COPE

Ian Henderson
COPE

Western Australia

Leanne Totten
Hepatitis C Nurse Coordinator
Fremantle Hospital

Larina Bromely
A/Coordinator
Hepatitis C Council Western Australia

Alan Philip
Chairperson
Hepatitis C Council Western Australia

Alan Quigley
Principal Medical Officer
Alcohol and Drug Authority

Lewis Marshall
Medical Coordinator
Sexual Health Program
Health Department Western Australia

Megan Scully
Advanced Community Nurse
Sexual Health Program
Health Department Western Australia

Kathryn Kerry
A/Program Coordinator
Sexual Health Program
Health Department Western Australia

Jude Bevan
Senior Project Officer
Sexual Health Program
Health Department Western Australia

Lindsay Mollison
Fremantle Hospital

Steve Whittred
Ministry of Justice

Mr Bob Wilson
Ministry of Justice

Michelle Kosky
Executive Director
Health Consumer Council (WA) Inc.
Chair, Australian National Council on AIDS and
Related Diseases Hepatitis C Sub-committee

Barbara Chester
Clinical Nurse Consultant
Hepatology/Liver Transplantation

Moira Sim
Alcohol and Drug Authority

Colleen Knight
Coordinator Needle and Syringe Exchange Program
Perth Aboriginal Medical Service

Ruth Wykes
Community Education
Western Australian AIDS Council

Wendy Loxley
Senior Research Fellow
National Centre for Research into the Prevention of
Drug Abuse
Curtin University of Technology
Western Australia

Susan Carruthers
PhD student
National Centre for Research into the Prevention of
Drug Abuse
Curtin University of Technology
Western Australia

Tamara Speed
Coordinator
Western Australian Substance Users Association

John Olynk
Senior Lecturer in Gastroenterology
Department of UDM

WD Reed
Head of Hepatology
Department of Medicine
University of Western Australia

Wendy Cheng
Gastroenterologist
Royal Perth Hospital

Marion McNery
Hepatitis C Nurse Counsellor
Gastroenterology Unit
Royal Perth Hospital

Queensland

Linda Selvey
Manager
Communicable Disease Unit
Queensland Department of Health

Jack Wallace
then Principal Program Adviser—Hepatitis C
Communicable Disease Unit
Queensland Department of Health
now Executive Director
Australian Hepatitis Council

Dr Elizabeth Powell
Director of Clinical Training/Liver Clinic
Princess Alexandra Hospital

Paul Sullivan
Project Officer
Queensland Needle Availability Support Program
John Chuah
Director, Gold Coast Sexual Health Clinic

Janya McCalman
Health Promotion Officer
Tropical Public Health Unit
Queensland Department of Health

Tony Falconer
Queensland Department of Health

Penelope Marshall, Principal Program Adviser
Communicable Disease Unit
Queensland Department of Health

Alexander Whightman
Education and Policy Manager
Queensland Intravenous AIDS Association

Lynne Biggs
Senior Project Officer
Queensland Department of Health

Paul Sullivan
Project Officer
Queensland Needle Availability Support Program

Keith Evan
State Alcohol and Tobacco Drug Services

Donna McLauchlin
A/Coordinator, Youth HIV/AIDS Program

Sarah Roberts
Youth Worker
Brisbane Youth Services

Victoria

John Carnie
Manager
Infectious Diseases Unit

Nick Crofts
MacFarlane Burnett Centre

Vivien Lin
Executive Director
Secretariat, National Public Health Partnership

Jill Meade
Coordinator, Hepatitis C Council

Katrina Watson
St Vincent's Hospital

John Spicer
Microbiology Department
Alfred Hospital
Chair Victorian AIDS and Related Diseases
Advisory Committee

Michael Batchelor
Acting Manager
STD/Blood Borne Virus Program

Richard Smith
AIDS Prevention and Support Unit

Judy Fisher
Haemophilia Foundation

Sandy Brite
Counsellor Victorian Haemophilia Foundation

Susan O'Callagan
Access Information Centre
Alfred Hospital

David Samson
AIDSLINE

Sandra Hamilton
AIDSLINE

New South Wales

Steven Hall
National Hepatitis C Education Program for
General Practitioners
Royal College of General Practitioners

Kate Dolan
National Drug and Alcohol Research Centre
University of New South Wales

Annie Madden
Coordinator
New South Wales Users and AIDS Association

Tony Rance
New South Wales Users and AIDS Association

Lisa Maher
National Drug and Alcohol Research Centre
University of New South Wales
Robert G. Batey
Department of Gastroenterology
John Hunter Hospital

Yvonne Thompson
Transfusion Related AIDS and Infectious Diseases
Service

Ross O'Donoughe
Director AIDS and Infectious Diseases Branch
New South Wales Department of Health

David Fowler
Manager HIV/AIDS and Hepatitis
New South Wales Department of Health

Ria Maximilien
Evaluation Officer, Demonstrated Projects
New South Wales Department of Health

Stuart Loveday, Paul Harvey
Hepatitis C Council of New South Wales

Jan Cregan
Hepatitis C Demonstration Project
Cumberland Hospital

Janice Jones
Hepatitis C Clinical Nurse Consultant and Hepatitis
C Project Coordinator
Central Sydney Demonstration Project
Royal Prince Alfred Hospital

Northern Territory

Margaret Neil
Manager
Alcohol and Other Drugs Council

Helen Mahrs
Department of Health and Aged Care

Daryl Themes
Aboriginal Medical Service

Wendy Hunter
Department of Corrective Services

Tasmania

Greg Stephens
Manager Sexual Health Branch
Department Health and Human Services

Julie Nahmani
Counsellor
Sexual Health Branch
Department Health and Human Services

Glenn Curran
Clinical Nurse Manager
Sexual Health Branch
Department Health and Human Services

Susan Folmer
Sexual Health Branch
Education/Community Development Officer
Department Health and Human Services

Geoff Farrell
Westmead Hospital
Chair Hepatology Section
Australian Society of Gastroenterologists

Alex Wodak
Alcohol and Drug Services
St Vincent's Hospital

Gillian Deakin
East Sydney Division of General Practice

Barry Horwood
AIDS Council
Jan Savage
Manager AIDS/STD Unit
Northern Territory Health Services

Kris Holden

Peter Lucas
AIDS/IDU Coordinator
Sexual Health Branch
Department Health and Human Services

Neil Cremasco
Clinical Nurse Counsellor
Public & Environmental Health
Department Health and Human Services

Angela Studley
Endoscopy Unit
Royal Hobart Hospital

Jenny Siddon
Coordinator Tasmanian Users Health and Support
League

Melinda Tonks
Tasmanian Council on AIDS and Related Diseases
(TASCARD)

Jenny Siddons
Coordinator Tasmanian Users Health and Support
League

Anna Talyor
Chairperson North West Hepatitis C Support Group

Australian Capital Territory

Paula Henriksen
Family Planning

Sera Pinwill
Workers in Sex Employment

Marge Macilwain
Counsellor Haemophilia Foundation

John Thompson
Australian Capital Territory Hepatitis C Council

Paul Pavli
Gastroenterologist
Liver Clinic
The Canberra Hospital

David Crosbie
Alcohol and Other Drugs Council of Australia

John Gregg
Youth Coalition of the Australian Capital Territory

Simon Rosenberg
Health Strategies Development Unit
Department of Health and Community Care

Fran Barry
Department of Health and Community Care

Lyndall Finn
Project Officer
Department of Health and Community Care

Deborah McKay
Project Coordinator
Australian Capital Territory Division of General
Practice Hepatitis C Project

Commonwealth Department of Health and Aged Care

Jan Bennett
Assistant Secretary National Population Health
Planning Branch
Population Health Division

Brendan Gibson
Director Evaluation and Research Uni
National Population Health Planning Branch
Population Health Division

Eamonn Murphy
Director HIV/AIDS & Hepatitis C Section
Communicable Diseases and Surveillance Branch
Population Health Division

Roger Hughes
Manager National Drug Strategy Unit
Drug Strategy Public Health Social Marketing
Branch
Population Health Division

Workshop participants, 23 July 1998

A workshop was held mid-way through the review in order to discuss the challenges identified and models for future management of hepatitis C at the national level. The following people attended the workshop:

Kim Petersen
Manager HIV/AIDS & Related Programs Unit
Communicable Disease Control Branch
South Australian Health Commission

Alan Thorpe
Assistant Director HIV/AIDS and Hepatitis C
Section
National Centre for Disease Control
Public Health Division
Department of Health and Aged Care

Jude Byrne
Australian Capital Territory Intravenous League

Doreen Rae
Health Project Officer
South Australia Offenders Services

Andrew Penman
Director New South Wales Cancer Council

Michael Batchelor
A/Manager STD/Blood Borne Virus Program
Victorian Department of Human Services

Ingrid van Beek
Director Kirketon Road Centre

David Fowler
Manager HIV/AIDS and Hepatitis C
New South Wales Department of Health

Jan Savage
Coordinator, AIDS/STD Unit
Disease Control Centre
Northern Territory Health Services

Jennifer Ross
Haemophilia Foundation Australia

Stuart Loveday
Executive Officer
Hepatitis C Council of New South Wales

Annie Madden
New South Wales Users & AIDS Association

Bob Batey
Director Gastroenterology Department
John Hunter Hospital
New South Wales

Mathew Law
National Centre in HIV Epidemiology and Clinical
Research

Gary Dowsett
Deputy Director Centre for the Study of Sexually
Transmitted Diseases

Peter McDonald
Chair Australian National Council on AIDS and
Related Diseases Clinical Trials and Treatments
Advisory Committee
Flinders University

Elizabeth Coates
Dental Service South Australia

William Sievert
Consultant Gastroenterologist
Department of Medicine
Monash Medical Centre
Melbourne

Roger Hughes
Manager Drug Strategy and Public Health Social
Marketing Branch
National Drug Strategy Unit
Population Health Division
Department of Health and Aged Care

Bill Bowtell

Catharina van Moort
Evaluation & Research Unit
National Population Health Planning Branch
Population Health Division
Department of Health and Aged Care

Jo Sexton
Principal Program Advisor
HIV/AIDS and Sexual Health Section
Queensland Department of Health

David Crosbie
Alcohol and Other Drugs Council of Australia

Ronald Glovers
Australian National Council on AIDS and Related
Diseases
Working group representative of Salvation Army

Katrina Watson
Deputy Directory Department of Gastroenterology
St Vincent's Hospital, Victoria

Kate Dolan
National Drug and Alcohol Research Centre
University of New South Wales

Robert Ali
Drug and Alcohol Services Council
South Australian Health Commission

Jude Bevan
Sexual Health Program
Health Department of Western Australia

Alan Shiell
Economist Department of Public Health and
Community Medicine
University of Sydney

Michael Brownjohn
Manager Offending Services

South Australia Offenders Services

Simon Rosenberg
Manager Health Strategies Development Unit
Australian National Territory Department of Health
and Community Care

Alexander Wightman
QUIVA

Debra Anthony
Assistant Commissioner
Department of Corrective Services

Fiona Brooke
A/Director HIV/AIDS and Hepatitis C Section
National Centre for Disease Control
Department of Health and Aged Care

Steven Hall
Royal Australian College of General Practitioners
Coordinator National Hep C Education Program for
General Practitioners

Gillian Deakin
Eastern Sydney Division of General Practitioners

Brendan Gibson
Director Evaluation and Research Unit
National Population Health Planning Branch
Population Health Division
Department of Health and Aged Care

Nick Crofts
MacFarlane Burnett Centre

John Kaldor
National Centre in HIV Epidemiology and Clinical
Research

Lou McCallum
Consultant

Apologies

Cathy Mead
Branch Head National Centre for Disease Control
Population Health Division
Commonwealth Department of Health and Aged
Care

Lewis Marshall
Medical Coordinator Communicable Diseases
Control Program
Health Department Western Australia

Leanne Totten
Hepatitis C Nurse Coordinator
Fremantle Hospital

Wendy Loxley
National Centre for Research into Prevention of
Drug Abuse, Western Australia

Anne Mijch
Infectious Diseases
The Alfred Hospital

Jack Wallace
Executive Director
Australian Hepatitis Council

Greg Stephens
Manager HIV/AIDS Unit
Tasmanian Department of Health and Community
Services

Vivian Lin
Executive Director
National Public Health Partnership
Department of Health and Family Services

John Carnie
Manager Infectious Diseases Unit
Victorian Department of Human Services

Alex Wodak
Director Alcohol & Drug Services
St Vincent's Hospital, Sydney

Jeff Ward
President Australian Hepatitis C Council

Susie McClean
Australian Federation of AIDS Organisations

Jim Butler
National Centre in Epidemiology and Population
Health
Australian National University

Aileen Plant
Department of Public Health
University of Western Australia

Chris Puplick
Chair Australian National Council on AIDS and
Related Diseases
New South Wales Anti-Discrimination Board

Grant Stewart
Australian National Council on AIDS and Related
Diseases Research Advisory Committee

Frances Byers
Evaluation and Research Unit
National Population Health Planning Branch
Population Health Division
Commonwealth Department of Health and Aged
Care

Neil Cremesco
Clinical Nurse
Public and Environmental Health
Tasmanian Department of Health and Community
Services

Linda Selvey
Director Communicable Disease Control Branch
Queensland Department of Health

Doreen Rosenthal
Director Centre for the Study of Sexually
Transmissible Diseases

Debra Reid
Chair Australian National Council on AIDS and
Related Diseases Indigenous Australians Sexual
Health Working Party

Michelle Kosky
Executive Director
Health Consumer Council (WA) Inc.
Chair Australian National Council on AIDS and
Related Diseases Hepatitis C Sub-committee

Note: Any inaccuracies in the lists of people interviewed and workshop participants are a result of the lists being compiled from administrative records.

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Appendix B Implementation of the recommendations of the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach

The extent of implementation of the National Hepatitis C Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach was determined in large part on the basis of a survey of the eight State and Territory health departments and the Commonwealth Department of Health and Aged Care. Tables B.1 and B.2 provide details of the information gained from the survey.

Table B.1 Implementation of the recommendations of the National Hepatitis C Action Plan

Recommendation	Responsibility	Implementation status, as reported	Effectiveness, as reported
Epidemiology and surveillance			
1 Use by the Commonwealth and all States and Territories of an appropriate and consistent definition of incident and prevalent cases of hepatitis C	All jurisdictions	Fully implemented in eight jurisdictions Partially implemented in one jurisdiction	Moderately effective in three jurisdictions Unstated by three jurisdictions Very effective in two jurisdictions Ineffective in one jurisdiction
2 Improved surveillance through a 12-month pilot study involving active follow-up of seropositive tests to enable the optimal ascertainment of incident cases and collection of information on risk factors for incident and prevalent cases	All jurisdictions	Fully implemented in six jurisdictions Partially implemented in two jurisdictions Not implemented in one jurisdiction	Moderately effective in five jurisdictions Unstated or unknown in two jurisdictions Ineffective in one jurisdiction
3.1 Systems operating for following up reports of cases of hepatitis C infection and collection of surveillance data	States and Territories	Fully implemented in four jurisdictions Partially implemented in two jurisdictions Unstated or not implemented in two jurisdictions	Unstated or unknown in four jurisdictions Moderately effective in three jurisdictions Ineffective in one jurisdiction
3.2 Uniform minimum data set developed and the collation and reporting of national data in <i>Communicable Diseases Intelligence</i>	Commonwealth	Fully implemented	Moderately effective/ineffective

Table B.1 (cont'd) Implementation of the recommendations of the National Hepatitis C Action Plan

Recommendation	Responsibility	Implementation status, as reported	Effectiveness, as reported
Testing			
4 The National HIV Reference Laboratory coordinates technical aspects of hepatitis C laboratory testing, including evaluation of test kits, quality control and quality assurance programs, and standard setting	Commonwealth and National HIV Reference Library	Implemented	Moderately effective
5 The Therapeutic Goods Administration has in place measures to evaluate and approve hepatitis C test kits as a condition of entry on the Australian Register of Therapeutic Goods	Commonwealth	Fully implemented	Moderately effective
7 The existence of appropriate protocols for the conduct of testing, addressing clinical and public health indications for testing, and which tests should be performed in specific circumstances	NHMRC	Fully implemented	Unstated
6.1 Approved first line tests for hepatitis C infection are widely available to pathology laboratories	Commonwealth	Fully implemented	Unstated
6.2 Specialised tests are available, with limitations on which laboratories are approved to conduct particular tests being consistent with testing protocols and TGA requirements	Commonwealth	Fully implemented	Moderately effective
Management, counselling and treatment of patients			
8.1 Adequate and appropriate counselling and referral services are available	States and Territories	Partially implemented in four jurisdictions Fully implemented in three jurisdictions Unstated by one jurisdiction	Moderately effective in five jurisdictions Unstated or unknown in three jurisdictions
8.2 Provision of counselling by suitably qualified health care workers to persons who have positive hepatitis C tests or whose status remains indeterminate	States and Territories and professional bodies	Partially implemented in five jurisdictions Fully implemented in three jurisdictions	Moderately effective in five jurisdictions Unstated or unknown in three jurisdictions
8.3 Referral of newly diagnosed positive and indeterminate patients to suitably qualified medical practitioners for follow-up	States and Territories and professional bodies	Partially implemented in six jurisdictions Fully implemented in two jurisdictions	Moderately effective in five jurisdictions Unstated or unknown by three jurisdictions
9.1 Diagnosis and clinical guidelines developed for the management of antibody positive or antibody indeterminate patients and the management of interferon	NHMRC	Fully implemented	Unknown

Table B.1 (cont'd) Implementation of the recommendations of the National Hepatitis C Action Plan

Recommendation	Responsibility	Implementation status, as reported	Effectiveness, as reported
9.2 Wide availability of professional development opportunities for medical and other health professionals, linked to diagnosis and clinical guidelines	All jurisdictions; professional bodies	Partially implemented	Unknown
10 Assistance to appropriate community based groups to address the support needs of people with hepatitis C	All jurisdictions	Partially implemented in four jurisdictions Unstated or unknown in three jurisdictions Fully implemented in two jurisdictions	Unstated or unknown in five jurisdictions Moderately effective in three jurisdictions Very effective in one jurisdiction
National approach to education and prevention			
11.1 A document outlining a coordinated national education approach with input from the Commonwealth, States and Territories, and community and professional groups	Commonwealth	Fully implemented	Unknown
11.2 Review conducted of number and type of education materials and training packages relating to hepatitis C (as at October 1994)	Commonwealth	Fully implemented	Unknown
12.1 Review conducted in late 1994/early 1995 of current education strategies for youth, injecting drug users, people with hepatitis C and health service providers, including drug and alcohol programs, to take account of hepatitis C	All jurisdictions	Partially implemented in six jurisdictions Fully implemented in three jurisdictions	Unstated or unknown in eight jurisdictions Moderately effective in one jurisdiction
12.2 Review in late 1994/early 1995 of occupational health and safety guidelines on exposure to blood and body fluids regarding adequacy to deal with hepatitis C	All jurisdictions	Partially implemented in five jurisdictions Fully implemented in two jurisdictions Unstated by two jurisdictions	Unstated or unknown in eight jurisdictions Moderately effective in one jurisdiction
13 Increased availability of sterile injecting equipment	States and Territories	Fully implemented in six jurisdictions Partially implemented in two jurisdictions	Unstated or unknown in four jurisdictions Very effective in one jurisdiction Moderately effective in two jurisdictions Ineffective in one jurisdiction

Table B.2 Implementation of the recommendations of the Nationally Coordinated Hepatitis C Education and Prevention Approach

Recommendation		Responsibility	Implementation status, as reported	Effectiveness, as reported
1	Injecting drug users	All jurisdictions; community-based organisations	Partially implemented in six jurisdictions Fully implemented in three jurisdictions Most of Commonwealth's responsibilities still to be implemented	Unstated or unknown in five jurisdictions Moderately effective in four jurisdictions
1.1	Enhanced needle and syringe exchange program achieved through development of outreach and other options to maximise access	States and Territories	Partially implemented in seven jurisdictions Fully implemented in one jurisdiction	Unstated or unknown in seven jurisdictions Moderately effective in one jurisdiction
1.2	Information resources and peer education interventions developed	All jurisdictions; community-based organisations	Partially implemented in eight jurisdictions Fully implemented in one jurisdiction	Unstated or unknown in eight jurisdictions Moderately effective in one jurisdiction
1.3	Harm minimisation strategies promoted	All jurisdictions; community-based organisations	Partially implemented in seven jurisdictions Unstated by two jurisdictions	Unstated by seven jurisdictions Moderately effective in two jurisdictions
1.4	Methadone programs expanded	States and Territories	Unstated or not implemented in six jurisdictions Partially implemented in two jurisdictions	Unstated by six jurisdictions Moderately effective in two jurisdictions
1.5	Policies for hepatitis C education and prevention programs developed	States and Territories, community-based organisations	Unstated or not implemented in six jurisdictions Partially implemented in two jurisdictions	Unstated or unknown in eight jurisdictions
1.6	Coordinated planning of hepatitis C education and prevention policy and programs	States and Territories, community-based organisations	Unstated or not implemented in six jurisdictions Partially implemented in two jurisdictions	Unstated or unknown in seven jurisdictions Moderately effective in one jurisdiction

Table B.2 (cont'd) Implementation of the recommendations of the Nationally Coordinated Hepatitis C Education and Prevention Approach

Recommendation	Responsibility	Implementation status, as reported	Effectiveness, as reported
2 Skin penetration specialists	States and Territories and local govts, Commonwealth, tattooists, infection control societies and environmental health officers	Partially implemented in four jurisdictions Fully implemented in three jurisdictions No activity in two jurisdictions	Unstated or unknown in seven jurisdictions Effective in one jurisdiction Moderately effective in one jurisdiction
2.1 Infection control and safe practice training programs provided for environmental health officers and skin penetration practitioners	States and Territories and local govts	Unstated or not implemented in four jurisdictions Partially implemented in four jurisdictions	Unstated by six jurisdictions Moderately effective in one jurisdiction Very effective in one jurisdiction
2.2 Education materials (print and audio-visual) developed for specific target groups	States and Territories and local govts, Commonwealth, tattooist organisations	Partially implemented in four jurisdictions Unstated implemented in three jurisdictions Fully implemented in two jurisdictions	Unstated by six jurisdictions Moderately effective in one jurisdiction Effective in two jurisdictions
2.3 [Revision of] legislation and standards regulating infection control practices for skin penetration activities	States and Territories and local govts	Unstated by four jurisdictions Partially implemented in two jurisdictions Fully implemented in two jurisdictions	Unstated by six jurisdictions Moderately effective in one jurisdiction Effective in one jurisdiction
2.4 Policy approaches to work practices of skin penetration practitioners developed by environmental health officers	States and Territories, infection control societies, environmental health officers	Partially effective in three jurisdictions Unstated by three jurisdictions Fully effective in two jurisdictions	Unstated by six jurisdictions Moderately effective in one jurisdiction Effective in one jurisdiction

Table B.2 (cont'd) Implementation of the recommendations of the Nationally Coordinated Hepatitis C Education and Prevention Approach

Recommendation		Responsibility	Implementation status, as reported	Effectiveness, as reported
3	General community	All jurisdictions; hepatitis C councils; injecting drug users organisations; drug companies; medical experts; community-based organisations	Partially implemented in five jurisdictions Fully implemented in three jurisdictions Partially implemented by Commonwealth	Unstated or unknown in five jurisdictions Moderately effective three jurisdictions Not effective in one jurisdiction
3.1	National Hepatitis C Awareness Week established	hepatitis C councils, injecting drug users organisations, drug companies	Not implemented	
3.2	Education of health and other appropriate journalists conducted	All jurisdictions; medical experts; community-based organisations	Not implemented	
3.3	Strategic associations established with key dental and medical associations and community-based organisations	All jurisdictions; hepatitis C councils; medical experts	Unstated by seven jurisdictions Partially implemented in one jurisdiction To be implemented in one jurisdiction	Unstated by eight jurisdictions Moderately effective in one jurisdiction

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3.4	Public relations strategy developed, including media kits	Commonwealth in consultation with community-based organisations	Unstated by all jurisdictions
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Table B.2 (cont'd) Implementation of the recommendations of the Nationally Coordinated Hepatitis C Education and Prevention Approach

Recommendation	Responsibility	Implementation status, as reported	Effectiveness, as reported
Other ie school education, community talks	Commonwealth in consultation with community-based organisations	Partially implemented in seven jurisdictions Unstated by two jurisdictions	Unstated by all jurisdictions
4 Decision and policy making	All jurisdictions; community-based organisations; professional organisations	Partially implemented in six jurisdictions Fully implemented in three jurisdictions	Unstated or unknown by four jurisdictions Moderately effective in four jurisdictions Very effective from Commonwealth perspective
4.1 Hepatitis C issues incorporated onto the agendas of HIV/AIDS Parliamentary Liaison Groups	Commonwealth and States and Territories	Partially effective in four jurisdictions Unstated or not implemented in four jurisdictions Fully implemented in one jurisdiction	Unstated by eight jurisdictions Effective in one jurisdiction
4.2 Regular national hepatitis C forums on prevention, treatment and care, surveillance and policy	States and Territories, community-based organisations and professional organisations	Unstated by six jurisdictions Partially implemented in two jurisdictions Fully implemented in one jurisdiction	Unstated by all jurisdictions
4.3 Relevant health and other conferences utilised to raise hepatitis C	Commonwealth and States and Territories	Unstated by seven jurisdictions Partially implemented in two jurisdictions	Unstated by seven jurisdictions Not effective in one jurisdiction Moderately effective in one jurisdiction

4.4	Hepatitis C as a regular agenda item of AHMAC and other high-level policy meetings (Ministerial Council on Drug Strategy, ANCARD, NHMRC)	Commonwealth	Partially implemented in seven jurisdictions Unstated by one jurisdiction Fully implemented in one jurisdiction	Unstated by five jurisdictions Moderately effective in three jurisdictions Effective in one jurisdiction
5	Custodial institutions	States and Territories, community-based organisations	Partially implemented in seven jurisdictions Not implemented in one state jurisdiction	Unstated or unknown by five jurisdictions Moderately effective in three jurisdictions

Table B.2 (cont'd) Implementation of the recommendations of the Nationally Coordinated Hepatitis C Education and Prevention Approach

Recommendation	Responsibility	Implementation status, as reported	Effectiveness, as reported
5.1 Availability of decontamination measures increased and availability of the means of prevention	States and Territories	Partially implemented in five jurisdictions Unstated or not implemented in three jurisdictions	Unstated by seven jurisdictions Not effective in one jurisdiction
5.2 Education services to inmates including training of inmates, peer education and production of resources	States and Territories and community-based organisations	Partially implemented in five jurisdictions Unstated by three jurisdictions	Unstated by all jurisdictions
5.3 Staff trained in infection control and prevention of transmission	States and Territories	Unstated by five jurisdictions Partially implemented in two jurisdictions Fully implemented in one jurisdiction	Unstated by seven jurisdictions Effective in one jurisdiction
5.4 Policy for hepatitis C education and prevention developed, planning for education and prevention programs conducted	States and Territories	Unstated or not implemented in six jurisdictions Partially implemented in two jurisdictions	Unstated by all jurisdictions
6.1 Health service providers: general	States and Territories, Commonwealth, community-based organisations, professional organisations	Partially implemented in seven jurisdictions Fully implemented in two jurisdictions	Unstated or unknown by five jurisdictions Moderately effective in three jurisdictions Very effective in one jurisdiction

6.1.1	Education materials developed and disseminated	Commonwealth, States and Territories and professional organisations	Partially implemented in five jurisdictions Fully implemented in two jurisdictions Unstated or not implemented in two jurisdictions	Unstated by seven jurisdictions Moderately effective in two jurisdictions
6.1.2	Training programs in prevention issues, lifestyle/behavioural change, and counselling and referral developed and implemented	States and Territories, community-based organisations and professional organisations	Unstated or not implemented in five jurisdictions Partially implemented in four jurisdictions	Unstated by seven jurisdictions Moderately effective in one jurisdiction Effective in one jurisdiction

Table B.2 (cont'd) Implementation of the recommendations of the Nationally Coordinated Hepatitis C Education and Prevention Approach

Recommendation	Responsibility	Implementation status, as reported	Effectiveness, as reported	
6.1.3	Supportive institutional policies developed	States and Territories and professional organisations	Moderately implemented in six jurisdictions Partially implemented in one jurisdiction Fully implemented in one jurisdiction	Unstated by seven jurisdictions Moderately effective in one jurisdiction
6.2	Health service providers: education for treatment, care and support	States and Territories, Commonwealth, community-based organisations	Partially implemented in seven jurisdictions Fully implemented in two jurisdictions	Unstated or unknown by six jurisdictions Moderately effective in two jurisdictions Very effective in one jurisdiction
6.2.1	Referral networks of suitably qualified counsellors exists	States and Territories and community-based organisations	Not formally implemented in all jurisdictions	
6.2.2	Education and training program for counsellors and psychologists developed	Commonwealth and States and Territories	Unstated or not priority in five jurisdictions Partially implemented in four jurisdictions	Unstated by all jurisdictions

6.2.3	Training programs on hepatitis C counselling for general practitioners developed	States and Territories, community-based organisations	Partially implemented in all jurisdictions with Commonwealth funding a project but responsibility not identified in recommendations	Unstated by all jurisdictions
6.2.4	Economic impact of hepatitis C investigated and documented	Commonwealth	Currently being undertaken	
6.3	Health service providers: prevention of occupational exposure risks	States and Territories, Commonwealth, community-based organisations	Partially implemented in six jurisdictions Fully implemented in three jurisdictions	Unstated or unknown by six jurisdictions Very effective in two jurisdictions Moderately effective in one jurisdiction

Table B.2 (cont'd) Implementation of the recommendations of the Nationally Coordinated Hepatitis C Education and Prevention Approach

Recommendation	Responsibility	Implementation status, as reported	Effectiveness, as reported
6.3.1 Curriculum development and in-service training for health service providers	States and Territories and professional associations	Unstated or not implemented in five jurisdictions Partially implemented in three jurisdictions	Unstated by seven jurisdictions Effective in one jurisdiction
6.3.2 Infection control procedures and workplace policies developed	NHMRC, AHMAC, States and Territories	Partially effective in six jurisdictions Unstated or not implemented in three jurisdictions	Unstated by seven jurisdictions Moderately effective in two jurisdictions
6.3.3 Intersectoral collaboration on nationally agreed policy direction and utilisation of existing program arrangements	Commonwealth and States and Territories	Unstated by all jurisdictions	Unstated by all jurisdictions
7 People affected by hepatitis C	States and Territories, Commonwealth, community-based organisations	Partially implemented in six jurisdictions Fully implemented in three jurisdictions	Unstated or unknown by five jurisdictions Moderately effective in four jurisdictions

7.1	<p>Appropriate support services developed:</p> <ul style="list-style-type: none"> - peer education - specialist counselling through relevant community and government services - telephone counselling 	<p>States and Territories and community-based organisations</p>	<p>Partially implemented in seven jurisdictions Unknown in one jurisdiction</p>	<p>Unstated or not effective by seven jurisdictions Moderately effective in one jurisdiction</p>
7.2	<p>Referral network for hepatitis C positive people developed to deal with discrimination issues, social support, family counselling and advocacy</p>	<p>States and Territories, community-based organisations and professional organisations</p>	<p>Partially implemented in five jurisdictions Unstated by three jurisdictions</p>	<p>Unstated or not effective in seven jurisdictions Moderately effective in one jurisdiction</p>
7.3	<p>Education materials and services (information and referral services, support groups for health monitoring and maintenance developed)</p>	<p>States and Territories and community-based organisations</p>	<p>Partially implemented in seven jurisdictions Unstated by one jurisdiction Work by Commonwealth but recommendations do not identify them as responsible</p>	<p>Unstated by seven jurisdictions Moderately effective in one jurisdiction</p>

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Appendix C Hepatitis C and the immune response: implications for vaccines

This appendix is the work of Scott Bowden and Stephen Locarnini, from the Victorian Infectious Diseases Reference Laboratory.

C.1 Vaccines

A large number of viral vaccines are in use today. Vaccines can be classified into three types: live attenuated vaccines, which constitute the bulk of most current viral vaccines (for example, the vaccines for measles, mumps, polio and rubella); inactivated vaccines, in which the virus has been chemically 'killed' (for example, 'flu vaccines); and sub-unit vaccines, in which a virus component has been synthesised by molecular techniques (for example, hepatitis B surface antigen from modified yeast cells). The major event that accelerated viral vaccine development was the ability to grow many viruses in cell culture. Both attenuated and inactivated vaccines rely on large amounts of virus being produced. Attenuated vaccines usually rely on serial passage of the virus in a cell culture system; the multiple propagation serves to reduce the virulence of the virus as it adapts to the new system of growth.

The two primary requirements of a vaccine are that it is safe, with a low level of side-effects, and efficacious, which is the ability to protect vaccine recipients from disease following subsequent exposure. Most vaccines are given prophylactically (that is, for protection) and efficacy depends generally on stimulation of the immune system components responsible for immunological memory (B and T lymphocytes). Vaccines can also be used therapeutically (after infection has been established) to try and boost the immune response to overcome infection. The efficacy of vaccines has been predicted by measuring the response of protective or neutralising antibodies (produced from B cells or B lymphocytes) after vaccination. More recently, the importance of the cell-mediated immune response (produced from T cells or T lymphocytes) has been documented and techniques have been developed to measure this parameter as well.

C.2 Immune response: general background

The initial response to viral infection involves a number of non-specific immune defences, including interferons and natural killer cells. After this non-specific response, acquired immunity takes over. The immune system produces specific antibodies to the infecting virus, as well as a specific cell-mediated or T cell response. The production of neutralising antibodies, capable of binding and inactivating the virus usually coincides with recovery from the infection and the development of immunity to re-infection. Viral antigens that stimulate the immune response to produce neutralising antibodies have formed the basis for most successful vaccines. The cell-mediated or T cell response involves production of cytotoxic T lymphocytes (Tc) and helper T lymphocytes (Th).

Antibodies are made by B lymphocytes ('B' from maturation in the bone marrow) when the lymphocyte comes into contact with a foreign antigen. The body designs the antibody molecule so that it has a recognition site complementary to a site on the antigen, enabling it to bind with great avidity. Antibody molecules also have other sites, allowing them to participate in secondary functions, including phagocytosis and activation of the complement cascade system, which result in clearance of the viral infection.

Under optimal conditions, it may be that vaccine-induced antibody can provide 'sterilising immunity', although recent data suggest that T lymphocytes (mature in the thymus gland) also make some contribution. Viruses replicating within cells may be shielded from the effects of circulating antibodies, so the body has developed a defence system based on the T lymphocytes to overcome this deficiency. Viral proteins produced inside a cell may be degraded into small units or peptides. These viral peptides become incorporated in cytoplasmic vacuoles or lysosomes where they associate with a molecule of the major histocompatibility complex (MHC). MHC molecules are host cell surface markers; class I MHC molecules are present on almost all cells in the body and thus are a cell marker, while class II MHC molecules appear on phagocytic macrophages and B cells. When the T lymphocyte recognises these two components together, it binds to the infected cell and becomes activated. In virally infected cells, the cytotoxic T cells (T_c) recognise the complex consisting of class I MHC and the viral peptide and kill the target cell by a number of cytotoxic mechanisms. Helper T cells (T_h) bring about the killing of viruses within macrophages by recognising the class II MHC and viral peptide on the surface and triggering release of activating factors, notably interferon, which in turn induce the macrophages to eliminate the virus.

C.3 Hepatitis C virus

Hepatitis C virus has been shown to be the major causative agent of parenteral non-A, non-B hepatitis. In most individuals infected with hepatitis C the virus persists, leading to the development of chronic liver disease, which in turn confers a high risk of hepatocellular carcinoma (Choo et al. 1989). Hepatitis C is a worldwide public health problem, with estimates of 100 million to 200 million chronic carriers. In Australia, it has been estimated that there are 200 000 individuals infected with the virus, with around 10,000 new cases per year. The vast majority of new cases are injecting drug users.

Much effort has gone into developing possible vaccines for hepatitis C but success has been limited. The inability to find a suitable system for growth of the virus in cell culture has hampered vaccine development, so any vaccine will rely on recombinant molecular methods for the production of the appropriate viral component(s). In addition, there is evidence of hepatitis C associating with host *B*-lipoproteins, which may help in masking the virus from attack by neutralising antibodies (Thomssen et al. 1992). Finally, the only animal model available to evaluate vaccines is the chimpanzee, which is impractical in most instances for both financial and ethical reasons.

As an initial step to developing a vaccine for hepatitis C, a greater understanding of the factors influencing the immune response to the virus will be necessary.

C.3.1 Viral heterogeneity

Since the discovery of the hepatitis C virus in 1989, nucleotide sequence data have accumulated showing that the RNA genome of the virus has considerable heterogeneity. When sequences have been compared between different hepatitis C isolates, phylogenetic analysis has shown that the virus can be classified into distinct genotypes, which in some instances can be further divided into subtypes (McCaw et al. 1997). Even in an individual infected with hepatitis C, the virus exists as a swarm of closely related but different quasi-species, one of which is usually dominant or most frequently represented (Shimuzu et al. 1994).

The heterogeneity is unevenly spread through the viral genome, with hypervariable regions located on the putative envelope proteins; these regions undergo frequent mutations during the course of infection. The quasi-species nature of hepatitis C provides the virus with an adaptation advantage, allowing for the rapid selection of the mutant fittest for any new environmental condition, such as when the immune system pressures the current dominant virus type.

C.3.2 Neutralising antibodies

With the hypervariable region being the region undergoing the most mutation, it is likely that this is the candidate region the immune system targets with neutralising antibodies. During chronic infection, however, continuous variation is occurring, with antibody-resistant variants being rapidly selected so that they can outstrip any potential neutralising antibodies raised. Indeed, mutations in the hypervariable regions of hepatitis C that show the loss of B cell epitopes have been documented (Weiner et al. 1992).

A number of studies have mapped the temporal appearance of antibodies to hepatitis C infection. Generally, antibodies to the core and envelope proteins appear first, soon after the onset of hepatitis, followed later by antibodies to the more immunogenic non-structural proteins NS3, NS4 and NS5. Despite the production of these multiple antibodies, hepatitis C infection persists in around 80 per cent of those infected, suggesting that these antibodies are unable to neutralise or clear the virus (Nelson & Lau 1996).

Sub-unit vaccines using recombinant envelope proteins have successfully protected chimps from infection but only with low dose hepatitis C challenge (Choo et al. 1994). In addition, high antibody titres were required and repeat vaccination resulted in reduction of antibody titre and susceptibility to re-challenge (Nelson & Lau 1996). Furthermore, relative weak immunity to hepatitis C was indicated by experiments in which chimpanzees previously infected with the virus were re-challenged. All chimps with apparently resolved infection showed some evidence of re-infection. Interestingly, even the majority of chimps with chronic infection showed some serological evidence of infection and episodes of biochemical hepatitis (Prince et al. 1994). The lack of protection from re-infection in chimps correlates with studies of multiply transfused thalassaemic patients who were shown by sequencing to have been infected on at least two separate occasions (Lai et al. 1994). Together, the findings suggest hepatitis C immunity is weak and that neutralising antibodies may be strain specific. This genetic

diversity of the virus suggests that for a hepatitis C sub-unit vaccine to successfully produce neutralising antibodies, a battery of closely related viral proteins would be required for it to be efficacious.

C.3.3 Cell-mediated immunity

The cellular immune response, or T cell response, is believed to limit hepatitis C replication. Cellular immune responses to recombinant core and envelope proteins have been reported (Koziel et al. 1993) and increased viral load and accelerated disease progression in immuno-suppressed patients indirectly supports the role that cell-mediated immunity inhibits viral replication (Gane et al. 1996; Soto et al. 1997). This correlates with the finding that patients with higher Tc activity have lower levels of viraemia (Nelson et al. 1997), although it must also be noted that other investigators have not found any such correlation (Koziel 1997).

Although the cellular immune response is likely to be important in the limiting and/or elimination of viral replication, it is also likely that it is responsible for the liver damage seen with chronic hepatitis C infection rather than a direct cytopathic effect caused by the virus. Supporting this view is the contention that patients with higher intrahepatic Tc activity have higher ALT levels and more active inflammation (Nelson et al. 1997). This is important for vaccine development because the aim will be to produce a sufficiently high immune response to eliminate the virus without exacerbating any liver damage.

With the lack of cell cultures for growth and suitable animal models to evaluate potential vaccines, researchers have developed a number of alternative systems. These include the synthesis of recombinant virus-like particles containing B and T cell epitopes (Baumert et al. 1998) and the use of DNA vaccination to elicit immune responses to hepatitis C in mice (Tedeshi et al. 1997). In recent years, direct DNA injection has been shown to be capable of inducing an immune response against viral infection. With this method, the injected animal processes the injected DNA to synthesise the viral proteins. These proteins are presented in the same conformation that would occur in a natural infection, important factors for the evaluation of the B and T cell responses. In this manner, Tc and Th epitopes can be identified and further tested for their ability to protect from infection.

C.4 Other obstacles to overcome in the development of hepatitis C vaccines

The high rate of chronicity associated with hepatitis C and the large number of chronic carriers worldwide make the development of an appropriate vaccine a high priority. But commercial considerations may play a role. The rate of new infection in developed countries is decreasing and the full costs of development and licensing are likely to be high. In less well developed countries, where the need may be greatest, health budgets are unlikely to sustain high-cost vaccination. It may be that the production of a prophylactic vaccine to prevent infection is passed over in favour of a therapeutic vaccine. This could be done either to interrupt the development of chronicity by vaccination after acute infection or to ameliorate the progression of chronic disease

based on boosting the cell-mediated response. It is to be hoped that one of these offers sufficient inducement for manufacturers to maintain and increase research and development.

C.5 Conclusion

The immune response to hepatitis C involves both antibody and cellular immune responses. The virus has hypervariable regions that appear to be important neutralisation sites. Mutations within the region, however, or selection of a minor type from the hepatitis C quasi-species allows the virus to escape, explaining why it is difficult to obtain immune protection. Challenge experiments showing that chimps previously infected could be re-infected illustrate that immunity is weak. It is unlikely that a vaccine based on production of neutralising antibodies alone would be sufficient to generate 'sterilising immunity'. Despite this, there is some optimism that vaccines can be effective. Vaccination in chimps of recombinant envelope proteins has shown low-level protection and more recent work has concentrated on the evaluation of the role of the cellular immune response. In natural infection, around 20 per cent of those infected do clear the virus. Further studies are necessary to determine the detail of why some individuals clear the virus while in others the virus persists. The key most probably lies with the cell-mediated response, and systems are being developed to define the most important immunological epitopes and evaluate their ability to protect people who are vaccinated from hepatitis C infection. Ideally, a hepatitis C vaccine will induce neutralising antibodies and prime the Tc and Th lymphocytes to a broad range of conserved viral epitopes.

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Abbreviations

AHMAC	Australian Health Ministers Advisory Council
AIDS	acquired immunodeficiency syndrome
ALT	alanine aminotransferase
ANCARD	Australian National Council on AIDS and Related Diseases
CARG	Commonwealth AIDS Research Grants
CDNANZ	Communicable Disease Network of Australia New Zealand
DNA	deoxyribonucleic acid
GP	general practitioner
HCV	hepatitis C virus
HIV	human immunodeficiency virus
IDU	injecting drug user
IGCARD	Intergovernmental Committee on AIDS and Related Diseases
NHMRC	National Health and Medical Research Council
NIROA	non-injecting routes of administration
PCR	polymerase chain reaction
RACGP	Royal Australian College of General Practitioners
RNA	ribonucleic acid
STD	sexually transmissible disease
TGA	Therapeutic Goods Administration