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Department of  
Health and  
Aged Care

# National Hepatitis C Strategy

1999–2000  
to 2003–2004

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# **National Hepatitis C Strategy**

1999–2000 to 2003–2004

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# Foreword

Australia is leading the international community in responding to the hepatitis C epidemic, and this pioneering strategic document establishes a comprehensive framework to guide future action. Australia is recognised as a world leader in developing and implementing effective population health responses to other blood-borne viruses—and now we aspire to mirror these achievements for hepatitis C. These earlier lessons and experiences provide us with a platform to launch a renewal of our efforts to deal with the serious impacts of hepatitis C within the Australian community.

The hepatitis C epidemic is already well established in our community—more than 200 000 Australians are already infected—and a sense of urgency and momentum is now called for in the next phase of our response to this serious communicable disease. Our knowledge of the factors affecting transmission and progression to advanced illness is evolving, but we cannot defer further action until all the pieces of the puzzle are in place: we must act now, using the best available evidence while still pursuing an improved knowledge base. Responding to the challenges identified in this Strategy will help us to prevent the burden of disease increasing for those directly affected by hepatitis C as well as for the broader community.

The priority areas for action identified in this Strategy have been developed in response to a national population health review process followed by extensive community consultation during 1999; they are also supported by advice from the nation's foremost experts on hepatitis C. The contributions of all participants in these processes, especially State and Territory governments, are acknowledged and much appreciated.

This Strategy establishes an important foundation for action—a partnership between people affected by hepatitis C, governments at all levels, and medical, scientific and health care professionals—and acknowledges the need to work in a collaborative, non-partisan manner with all members of the partnership.

The Strategy also acknowledges that our response to hepatitis C cannot operate in isolation. Accordingly, it stresses the importance of establishing and maintaining operational links with other national population health strategies, in particular those concerned with HIV/AIDS and other blood-borne viruses,

the health of young people, the health of Aboriginal and Torres Strait Islander people, mental health policy, and policies and programs to improve the health of people living in rural, regional and remote areas of Australia.

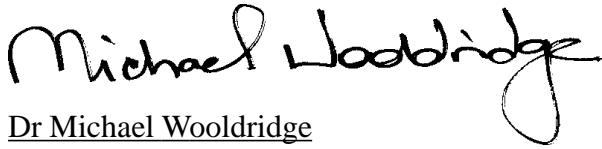
With over 90 per cent of all new hepatitis C infections occurring among people who inject drugs, the increasing use and injection of illicit drugs in Australia will have a powerful influence on the course of the hepatitis C epidemic here. The increased visibility of this serious population health problem has led to growing demand for, and pressure on, harm-reduction initiatives such as needle and syringe programs. In spite of this, preventing further transmission of hepatitis C remains a paramount concern, and these essential prevention measures must be maintained and, more importantly, enhanced. Preventing high risk behaviours such as injecting drug use will also be a valuable contribution to the aims of this Strategy. As a result, links and opportunities for joint efforts will be explored with the *National Drug Strategic Framework 1998–99 to 2002–03*, to ensure that health-promotion messages are well coordinated.

There are significant opportunities for coordinated efforts in many population health areas, particularly education, prevention and research. By situating this Strategy within a broader communicable diseases framework we create the opportunity to ensure that the overall health outcomes achieved are greater than the sum of the individual parts. It is the links between, and the integration of, these responses that will ensure both sustainability and maximum population health impact.

The Strategy has been drafted to operate as a flexible framework for responding to the challenges and opportunities that have been identified, as well as those that will undoubtedly emerge during the Strategy's five-year term. The Australian National Council on AIDS, Hepatitis C and Related Diseases will report to me on the Strategy's implementation and how best to respond to the challenges that have already been identified as well as those that emerge over time.

Successful implementation of the Strategy will depend on cooperation between the Commonwealth and State and Territory governments. The Strategy provides State and Territory governments with the flexibility to respond to the particular demands of the epidemic in their jurisdictions, while at the same time providing a framework for ensuring that consistent national standards are maintained. The Commonwealth will continue its strong leadership role in the Australian response to hepatitis C.

I commend to you the *National Hepatitis C Strategy 1999–2000 to 2003–2004*. It is my belief that this Strategy will consolidate the cooperative national approach to hepatitis C that has already been established and will provide an effective, flexible framework for responding to future challenges the epidemic may present.



Dr Michael Wooldridge  
Minister for Health and Aged Care

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# 1 Introduction

Hepatitis C is now the most commonly notified communicable disease in Australia. It poses a serious threat to population health.

The *National Hepatitis C Strategy 1999–2000 to 2003–2004* provides for a strong and inclusive response from all levels of government, community organisations, the medical, health care, scientific and research communities, and people affected by hepatitis C. \* People affected by hepatitis C are central to the success of this Strategy, which aims to meet both their collective and their individual needs and to reduce the hepatitis C epidemic's future impact on the Australian population.

The Strategy links with government policies to reduce the impact of illicit drug use and with population health policies dealing with HIV/AIDS and other blood borne viruses. In addition, it builds on the achievements of the *National Hepatitis C Action Plan* (AHMAC 1994), the *Nationally Coordinated Hepatitis C Education and Prevention Approach* (AHMAC 1995) and successive national HIV/AIDS strategies, including the current *National HIV/AIDS Strategy: Changes and Challenges* (Department of Health and Aged Care 2000).

## 1.1 The purpose of the Strategy

The *National Hepatitis C Strategy 1999–2000 to 2003–2004* aims to promote and support the health, safety and wellbeing of all Australians in relation to hepatitis C. It acknowledges that the most effective way to reduce the harms to individuals and the community that result from hepatitis C infection is to prevent exposure to the virus. At the same time, however, it recognises the need to support access to suitable treatments and to provide care and support for those affected. To achieve this, the Strategy has two primary aims:

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

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\* Throughout this Strategy document references to 'people affected by hepatitis C' should be taken to mean people at risk of infection, people with existing infection, and others (such as carers and partners) who are also affected by the epidemic.

The Strategy recognises that, regardless of how hepatitis C infection is acquired, the social, medical and economic impacts for the individual and the broader community are profound, with implications for affected people and for Australia's health care system. An effective national response to hepatitis C will be achieved through responding to the challenges and building on the opportunities outlined in the four priority areas for action, which are:

- reducing hepatitis C transmission in the community
- treatment of hepatitis C infection
- health maintenance, care and support for people affected by hepatitis C
- preventing discrimination and reducing stigma and isolation.

The Strategy is based on six essential components, which are considered fundamental to developing effective responses in the four priority areas. These essential components are:

- developing partnerships and involving affected communities
- access and equity
- harm reduction
- health promotion
- research and surveillance
- linked strategies and infrastructures.

Hepatitis C transmission depends on blood-to-blood contact, so the Strategy focuses on risk factors and specific circumstances of transmission rather than on specific population groups. The Strategy does, however, identify the need for improved access to health care services for Aboriginal and Torres Strait Islander communities and people from other cultural groups.

Many people with hepatitis C have experienced discrimination and stigmatisation. This can lead to social isolation and marginalisation and thus limit a person's access to information and health care services and create a disabling environment, so that the person has less opportunity to maintain and protect their own health. Health outcomes for all will be improved by preventing discrimination and alleviating the stigma and isolation that many people affected by hepatitis C experience. Action in this priority area will be essential if the Strategy's objectives are to be achieved.

## 1.2 The epidemiology of hepatitis C in Australia

### 1.2.1 Viral hepatitis

‘Hepatitis’ means inflammation of the liver. Such inflammation damages liver cells and can be caused by chemicals, harmful or hazardous alcohol consumption, disordered immune mechanisms, drugs or viruses.

Several types of hepatitis infection have been identified to date:

- Hepatitis A is usually a mild disease that does not become chronic. It is transmitted through food and water that has been contaminated with faecal matter from an infected person and occasionally via oral sexual contact or blood-to-blood contact during the infectious stage. A vaccine is available to protect against hepatitis A infection.
- Hepatitis B can be mild, severe, acute or chronic. It is transmitted through unprotected sexual intercourse, blood-to-blood contact, or from mother to child during pregnancy or at birth. It is not transmitted through contaminated food or water. A vaccine is available to protect against hepatitis B infection.
- Hepatitis C is transmitted predominantly through blood-to-blood contact—as can occur, for example, through sharing drug-injecting equipment. A specific laboratory test for hepatitis C has been available only since early 1990. There are at least nine different genotypes, or strains, of hepatitis C. Previous infection with one strain of the virus does not protect against re-infection with the same or a different strain. The seroconversion ‘window period’ ranges from 54 to 192 days, during which time antibodies cannot be detected. Nucleic acid testing, a new technology introduced in Australia from June 2000, can detect the virus directly; it effectively reduces the window period to 23 days, on average. At present there is no vaccine to protect against hepatitis C.
- Other types of hepatitis virus (D through to G) have also been isolated, but there is limited information about their epidemiology in Australia and insufficient evidence of their impact on individuals’ health.

### How hepatitis C affects individuals and the community: a summary

Hepatitis C infection involves an initial (acute) phase of infection, which is often asymptomatic and usually lasts from two to six months. During this phase levels of the virus in the blood rise dramatically until the body's immune response starts producing antibodies. Although these antibodies fight the virus, around 65 to 85 per cent of people infected will develop a long-term (chronic) infection and could transmit the virus to others. Many people with a chronic infection stay healthy for a long time. Some people develop symptoms of liver disease, among them tiredness, lethargy, nausea, headaches, depression, aches and pains in joints and muscles, and discomfort in the upper abdomen area. After many years a number of people with chronic infection will develop serious liver illness, such as cirrhosis, liver failure and liver cancer.

The hepatitis C virus is believed to have been in the Australian community for many years, possibly since the 1960s. Current estimates suggest that more than 200 000 Australians have been infected with the virus and that 11 000 new infections are occurring each year. In 1997 it was estimated that the cost of the hepatitis C epidemic in Australia was \$107.5 million, rising by \$46.6 million (over 50 years) for every 1000 new infections. With high numbers of existing chronic infections and most people with hepatitis C not yet seeking treatment or experiencing serious liver illness, compounded by the number of new infections occurring, hepatitis C will continue to have serious implications for Australia's health care system for many years.

### 1.2.2 Risk factors

Hepatitis C is transmitted through blood-to-blood contact. To date, the majority of hepatitis C infections in Australia have been caused either by sharing injecting equipment among people who inject drugs (80 per cent) or (before 1990—see below) by transfusion of blood products (5–10 per cent) (ANCARD Hepatitis C Sub-committee 1998). Other people may have become infected with hepatitis C through:

- non-sterile medical or dental procedures—in particular for people born in countries where the prevalence of hepatitis C is relatively high (Egypt and other countries in the Middle East, southern Europe, Asia, Africa)



- non-sterile tattooing, body-piercing or other skin-incision procedures
- needlestick injuries and accidental exposure to infected blood or blood products
- some other form of blood-to-blood contact
- mother-to-child transmission during pregnancy and delivery—an approximately 6 per cent risk if the mother has chronic hepatitis C and detectable viraemia (Dore et al. 1997).

During the 1970s and 1980s a small proportion of people who received blood transfusions (1–2 per cent in Australia) developed hepatitis but tested negative for hepatitis A and B. Following the discovery of the hepatitis C virus in 1989 and the development of an antibody test for its detection in 1990 it was found that approximately 90 per cent of these non-A, non-B post-transfusion hepatitis cases were caused by the hepatitis C virus (NHMRC 1994). Since 1990 all blood has been screened for hepatitis C antibodies, and since the introduction of nucleic acid testing for hepatitis C from June 2000 the risk of transmission through blood transfusions in Australia is very low.

Because the risk is considered very low, hepatitis C is not defined as a sexually transmissible infection, although sexual transmission is possible and has been documented (MacDonald & Wodak 1999).

Hepatitis C is not passed on through social contact such as hugging, kissing, sneezing or coughing. Sharing food, drinks, plates, eating utensils, laundry or toilet facilities are not considered risk factors for transmission. On the other hand, sharing of toothbrushes, razors or other personal hygiene items is not recommended given the potential for exposure to blood (Department of Health and Family Services 1998, see also Dolan 1997). Mosquitoes or other insects do not transmit hepatitis C (Cams 1994). The risk of transmission of hepatitis C through medical procedures in Australia is also considered minimal because of the introduction of Standard Precautions for infection control.

### 1.2.3 Incarceration: a high risk context

A history of incarceration is independently associated with hepatitis C transmission, and the custodial setting compounds the risks for hepatitis C transmission. This elevated risk is the result of the high prevalence of hepatitis C infection among custodial populations and the prevalence of high risk behaviours within these institutions. In this context, ‘custodial settings’

includes prisons, juvenile justice centres, and remand and other detention centres.

Around 50 per cent of people in custodial settings report a history of injecting drug use (Butler et al 1997) and some studies have found that as many as 66 per cent of people entering the custodial system have hepatitis C (Butler 1997). Furthermore, a significant proportion of people (around 25 per cent) continue to inject while in custody and, in the absence of harm reduction measures, this group reports extremely high rates (about 90 per cent) of sharing injecting equipment (Dolan et al 1999). Research also shows that 10 per cent of inmates are initiated into drug-injecting practices whilst in custodial settings (Dolan et al 1999).

#### 1.2.4 The prevalence and incidence of hepatitis C

Current estimates suggest that over 200 000 people in Australia have been infected with hepatitis C; of these, an estimated 134 000 have developed chronic hepatitis C infection. In addition, it is estimated that 11 000 new infections occur each year (ANCARD Hepatitis C Sub-committee 1998). To the end of 1998 approximately 128 000 diagnoses of hepatitis C infection have been notified to the National Notifiable Diseases Surveillance System (NCHECR 1999). Estimates of hepatitis C prevalence (the total number of people infected at any specific time) and incidence (the number of people newly infected each year) are affected by the limitations of current testing technology, which does not differentiate between recent and chronic infection.

#### 1.2.5 The natural history of the virus

A recent review (Dore 2000) of the natural history of hepatitis C found that if 100 people are infected with the virus the outcome will be as follows:

- about 15 to 35 people will clear the virus spontaneously within two to six months of infection and will neither develop a chronic infection nor risk developing advanced liver disease. These people can, however, be re-infected with hepatitis C if they are re-exposed
- about 65 to 85 people will develop chronic hepatitis C infection
- about five to 10 people with chronic hepatitis C infection will have progressed to cirrhosis after 20 years of infection (rising to 20 people after 40 years of infection). Among the factors associated with an

increased risk of cirrhosis are alcohol consumption, HIV or hepatitis B co-infection, older age at the time of infection, and being male

- about three to five people with hepatitis C related cirrhosis will be at risk of liver failure or hepatocellular carcinoma after 30 to 40 years of infection. Among people with cirrhosis, the risk of liver cancer is 1 to 3 per cent a year
- the majority of people with chronic hepatitis C infection will probably not progress to advanced liver disease but their quality of life may be diminished.

Importantly, large numbers of people with hepatitis C are at present asymptomatic and not yet seeking testing or treatment. With increasing public awareness and changes in the health status of people with hepatitis C, however, it is anticipated that there will be a big increase in the demand for treatments and care and support services.

### 1.2.6 The economic impact of hepatitis C

The cost of hepatitis C to the Australian community has recently been calculated (Shiell 1998). Conservative estimates of direct and indirect costs in 1996–97 amount to \$107.5 million for people with existing infection, with costs rising by \$46.6 million (over 50 years) for every 1000 new infections. Considering the high numbers of existing chronic infections in Australia, coupled with the current incidence of approximately 11 000 a year, this epidemic will continue to have serious implications for Australia's health care sector for many years.

## 1.3 Australia's response to date

Australia is leading the world in responding to the hepatitis C epidemic and has developed this pioneering Strategy document to guide future action.

Population health action related to hepatitis C began in February 1990, when screening of the blood supply was promptly introduced following identification of the virus and the development of a suitable test. As part of the continuing efforts to keep abreast of best international standards, nucleic acid testing was introduced from June 2000 to further reduce the risk of hepatitis C transmission through transfusion of fresh blood products.

Australia also responded quickly by establishing, in May 1993, a joint task force between the Australian Health Ministers Advisory Council and the National Health and Medical Research Council.

In October 1994 AHMAC released the *National Hepatitis C Action Plan*, a document detailing the first nationally coordinated approach and identifying four priority areas for action: epidemiology and surveillance; testing; counselling and treatment; and education and prevention. The document described the roles and responsibilities of Commonwealth and State and Territory governments, the medical and research communities, and community organisations; it also acknowledged the vital role played by all these groups in the response to hepatitis C.

In 1995 AHMAC released a document entitled the *Nationally Coordinated Hepatitis C Education and Prevention Approach*, which described a program of education activities and was developed in consultation with representatives of the AHMAC National Hepatitis C Education and Prevention Reference Group.

Inclusion of hepatitis C under the aegis of the *National HIV/AIDS Strategy 1996–97 to 1998–99* strengthened the commitment to tackling the epidemic. That Strategy provided a basis for developing and extending partnerships in hepatitis C, emphasised collaboration, and raised the profile of hepatitis C as a priority on the population health agenda.

A review of the population health response to hepatitis C began in 1998 and the resultant report, *Hepatitis C: a review of Australia's response*, was published in January 1999. The review assessed the performance of the *National Hepatitis C Action Plan* and the *Nationally Coordinated Hepatitis C Education and Prevention Approach* and found the Action Plan had served Australia well by taking steps to deal with hepatitis C at a relatively early stage and mobilising the initial response to the epidemic (Lowe & Cotton 1999).

The important role of State and Territory governments in providing hepatitis C health promotion programs and primary health care planning and infrastructure is also acknowledged. Throughout the 1990s the various jurisdictions have implemented a range of initiatives and interventions aimed at reducing transmission of hepatitis C and minimising the impact for those already affected. In particular, inclusion of hepatitis C under the aegis of the third *National HIV/AIDS Strategy* provided State and Territory governments with the opportunity to capitalise on established programs and infrastructures

that targeted common risk factors (such as injecting drug use) and broaden the scope of these initiatives to incorporate hepatitis C related matters.

State and Territory governments also implemented Lookback programs designed to trace recipients, and in some jurisdictions donors, of contaminated blood or blood products before the introduction of screening of the blood supply. These people were then offered counselling and testing and, where necessary, provided with information on hepatitis C treatments and health maintenance and monitoring.

This *National Hepatitis C Strategy* recognises the important contribution to hepatitis C prevention efforts made by needle and syringe programs, which were originally implemented under successive national HIV/AIDS strategies. The 1998 review of Australia's response to hepatitis C concluded that these programs represented a 'blue-chip investment' in terms of cost-effectiveness, offering significant health gains, financial savings, and other benefits (Lowe & Cotton 1999). Support for this prevention mechanism will continue under the *National Hepatitis C Strategy*.

The contribution of organisations representing affected communities has been critical in drawing attention to the needs of people with hepatitis C and those at risk of acquiring this infection. The prevention and education measures and the care and support services developed and implemented through affected communities and their organisations continue to be vital in reducing hepatitis C transmission and mitigating the effects of infection.

The then Australian National Council on AIDS and Related Diseases gave hepatitis C a platform at the national advisory level. The newly established (1999) Australian National Council on AIDS, Hepatitis C and Related Diseases aims to build on this achievement by providing the Federal Minister for Health and Aged Care with independent expert advice on the national response to hepatitis C outlined in this Strategy. The importance of hepatitis C as a significant population health issue is also demonstrated in its reflection in the title of the ministerial advisory committee.

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## 2 The essential components of Australia's response

The success of the *National Hepatitis C Strategy 1999–2000 to 2003–2004* will depend on a number of components that underpin the development of national and State and Territory approaches to responding to the four priority areas, which are:

- reducing hepatitis C transmission in the community
- treatment of hepatitis C infection
- health maintenance, care and support for people affected by hepatitis C
- preventing discrimination and reducing stigma and isolation.

The essential components, listed below, are complementary and non-hierarchical, and they will collectively contribute to, and sustain, the national population health response to hepatitis C.

Lessons learnt from other population health strategies, as well as the 1998 review of Australia's response to hepatitis C, informed the process of identifying these components. The components were also strongly supported in the public forums convened and the written submissions received as part of the national consultations associated with the Strategy's development.

There are six essential components of Australia's response to hepatitis C in the five years to 2003–04:

- developing partnerships and involving affected communities
- access and equity
- harm reduction
- health promotion
- research and surveillance
- linked strategies and infrastructures.

## 2.1 Developing partnerships and involving affected communities

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

The *National Hepatitis C Strategy* establishes a partnership, as an inclusive approach, that will:

- share a commitment to the aims of the *National Hepatitis C Strategy*
- value the diversity of views and expertise within the partnership
- foster continuing dialogue between partners
- draw on expertise from various disciplines
- collaborate, consult and coordinate across diverse sectors
- support partnership members in fulfilling their roles and responsibilities.

The Strategy acknowledges that the involvement of affected communities is critical. The Strategy also represents a commitment by partners to act in ways that will strengthen and broaden the partnership.

## 2.2 Access and equity

People affected by hepatitis C do not make up a homogeneous group or community. In the design, implementation and evaluation of interventions and services attention must be paid to the diverse cultural, geographic, social and economic circumstances of people affected by the virus.

Access to the full range of prevention, education, treatment, care and support services should be improved for a range of people affected by hepatitis C, among them the following:

- people who inject drugs
- people in custodial settings



- people living outside large urban areas affected by hepatitis C
- people from culturally and linguistically diverse backgrounds affected by hepatitis C
- Aboriginal and Torres Strait Islander people affected by hepatitis C.

Interventions within the priority areas identified for this Strategy also need to be developed with regard to the broader context of the needs and problems facing people affected by hepatitis C. Social determinants of health such as employment, access to all levels of health services, quality of housing, educational opportunities and, more generally, social and community engagement affect a person's ability to gain access to the information and services that aim to reduce hepatitis C transmission and minimise the impacts of infection.

It is widely acknowledged that the stigma associated with hepatitis C infection arises from the association with injecting drug use and the fear of contagion. This stigma, and the discrimination that stems from it, can lead to social isolation and the marginalisation of people affected by hepatitis C. Discrimination takes many forms and seriously limits a person's ability to obtain and make use of information and services.

Limited access to information and services and discriminatory behaviour from service providers both act to limit a person's opportunities to prevent infection and subsequent illness and to initiate action to take care of themselves and make healthier lifestyle choices.

In summary, improved health outcomes for people with or at risk of hepatitis C—and consequently for the broader community—will be fostered through:

- provision of accessible information and services that recognise the unique characteristics of local communities
- working with health systems to meet the needs of all people affected by hepatitis C
- ensuring adherence to anti-discrimination legislation and promoting non-discriminatory behaviour by all service providers involved in the response to this major population health problem.

## 2.3 Harm reduction

The *National Drug Strategic Framework 1998–99 to 2002–03* states that governments do not condone illegal behaviours such as injecting drug use but they do acknowledge that these behaviours occur. It also states that governments have a responsibility to develop and implement population health measures designed to reduce the injury that such behaviours can cause, both to individuals and to the community.

Harm reduction interventions are designed to reduce drug related harm, such as transmission of hepatitis C, both for individuals and communities. When they are appropriate to particular environments and audiences, such interventions improve health, social and economic outcomes for individuals and the community. They seek to balance the cost to the community and to individuals of illegal or risk behaviours where those behaviours are associated with transmission of blood borne viruses such as hepatitis C and HIV. Under this *National Hepatitis C Strategy* ‘harm reduction interventions’ means interventions that aim to prevent anticipated harm (through activities directed at preventing hepatitis C transmission) as well as interventions that aim to reduce actual harm (through health education and protection activities and services for people with hepatitis C).

Harm reduction interventions sit within the spectrum of integrated approaches to drug use, under the banner of ‘harm minimisation’. This spectrum of approaches, within the *National Drug Strategic Framework*, includes supply reduction and demand reduction interventions.

There is compelling evidence that harm reduction interventions such as peer education and needle and syringe programs continue to be highly effective in reducing risk behaviour and the transmission of blood borne viruses such as HIV among people who inject drugs (Crofts et al. 1996, Department of Human Services and Health 1995, US Department of Human Services and Health 1998). There is also evidence emerging that these interventions are having a significant impact on transmission of hepatitis C in Australia (MacDonald et al. 2000). Research has also demonstrated that harm reduction interventions do not promote injecting drug use (Watters et al. 1994, US Department of Human Services and Health 1998).

A variety of interventions appropriate to the particular contexts where risk-taking behaviours occur will be supported and promoted under this Strategy. The primary focus for these interventions is to reduce transmission

of hepatitis C. The interventions will complement harm and demand reduction initiatives developed under the aegis of the *National Drug Strategic Framework*.

## 2.4 Health promotion

There is a national commitment to reduce the social, health and economic impacts of hepatitis C infection, both for the general community and for people affected by hepatitis C. Health promotion is critical in this, especially for people at risk of infection and people already affected by hepatitis C.

The principles of the 1986 *Ottawa Charter for Health Promotion* are at the basis of this Strategy. The Charter identifies five important ways in which individuals, communities and governments can act to improve their health:

- building healthy public policy
- creating supportive environments
- strengthening community action
- developing personal skills
- re-orienting health services.

Health promotion activities include disease prevention, education, social mobilisation and advocacy. Good health promotion recognises the political, economic, social, cultural, environmental, behavioural and biological determinants of health. To be most effective, health promotion programs emphasise local needs as well as the differing social, cultural and economic conditions in society at large.

The *National Hepatitis C Strategy* also embraces a diversity of educational approaches that are fundamental to reducing the rate of hepatitis C transmission; reducing discrimination; informing treatment providers, health care professionals and allied health care workers; and improving care and support services. Using a mixture of approaches and focusing on specific settings and circumstances, the following will be among the health promotion activities supported by the Strategy:

- peer education
- public education and campaigns

- professional education and training
- self-directed learning
- school-based education.

Health promotion activities, informed by the best available evidence and program logic, are an important component of the response in each of the Strategy's priority areas.

## 2.5 Research and surveillance

Although understanding of the hepatitis C epidemic has improved greatly in the last decade our knowledge remains incomplete. Research and surveillance are fundamental to achieving the aims of the *National Hepatitis C Strategy* and providing guidance for the national response. They are crucial to providing an evidence base for the development of public policy and programs, clinical treatments and therapies, and services that are compatible with the evolving needs of people affected by hepatitis C.

The main branches of research contributing to the population health effort to address hepatitis C are epidemiology, basic scientific research, virology, clinical research, and social and behavioural research.

The following principles should underpin research into hepatitis C:

- The contribution of basic science and virological, clinical, epidemiological, and social research to achieving the aims of the Strategy must be acknowledged.
- Research focused on both national and local issues is needed to guide the population health response and reflect differing contexts.
- Both investigator-initiated and commissioned research have a role in guiding the national response.
- The research–practice interrelationship should be fostered through sustainable mechanisms.
- Multi-disciplinary collaboration is encouraged.
- Community involvement is necessary in setting the research agenda, in the design and execution of research, and in disseminating the results.

To accommodate the diversity of circumstances and contexts affecting the population health response to hepatitis C, a balance is needed between research that has the capacity to guide important aspects of the national response (including policy formulation and health promotion interventions) and local research initiatives that investigate unique contexts and circumstances. Initiatives from within local communities are also recognised for their contribution towards developing innovative approaches.

International cooperation is essential to the further development of our understanding of the basic virology of the hepatitis C virus and of effective treatments and vaccines. Notwithstanding this, investment in basic research in Australia is justified to ensure a better understanding of the virus in Australia, to foster high calibre local researchers able to respond to international research developments, and because the local epidemic is characterised by a genotype diversity unique to Australia.

In this regard the National Health and Medical Research Council plays an important role in guiding and funding hepatitis C related research. It has specific responsibility for:

- raising the standards of individual and population health throughout Australia
- fostering the development of consistent health standards between the various States and Territories
- fostering medical research and training and population health research and training throughout Australia
- fostering consideration of ethical matters relating to health.

To maintain the currency and consistency of the research effort, the Australian National Council on AIDS, Hepatitis C and Related Diseases will annually review research priorities for hepatitis C and promote these to investigators and funding agencies to guide the direction of investigator-initiated projects. These priorities will help to identify research commissioned for strategic purposes and form a basis for supporting a balanced approach between basic science and virological clinical, epidemiological, and social and behavioural research.

Improved monitoring and surveillance of the hepatitis C epidemic in Australia are necessary to provide information to support the implementation of this Strategy. Surveillance mechanisms are used to monitor the prevalence and incidence of hepatitis C in our community, to identify those at risk of

infection and so enable accurate targeting of prevention and care interventions, and to provide data to assist in the evaluation of these interventions.

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

## 2.6 Linked strategies and infrastructures

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

The way Australia responds to illicit drug use will have a powerful influence on the future course of the hepatitis C epidemic. Hepatitis C infection is recognised as a major drug related harm within the *National Drug Strategic Framework*. Links and opportunities for joint efforts will be explored within the Framework to ensure coordinated health promotion messages and interventions and reduced duplication of effort.

At the national level, the coordination of activity, policy development and evaluation is linked with the *National HIV/AIDS Strategy* under the aegis of the Australian National Council on AIDS, Hepatitis C and Related Diseases and the Commonwealth–State–Territory Government Forum. These entities share responsibility for monitoring and overseeing the implementation of both the *National Hepatitis C Strategy* and the *National HIV/AIDS Strategy*.

Implementation also needs to be linked with Aboriginal and Torres Strait Islander health policy and program frameworks such as the *National Indigenous Australians' Sexual Health Strategy*, the Aboriginal Health Framework Agreements, and the *National Aboriginal Health Strategy*.

*Healthy Horizons: a framework for improving the health of rural, regional and remote Australians, 1999–2003* is a joint development of the National Rural Health Policy Forum and the National Rural Health Alliance for the Australian Health Ministers Conference. This framework includes the Regional Health Services Program and supports the development of strategies and infrastructures designed to improve access to health services for people living in rural, regional and remote areas. Implementation of the *National Hepatitis C Strategy* in these areas will benefit from coordination with initiatives under this framework.

As other national population health initiatives are developed during the term of the *National Hepatitis C Strategy* links will be established where appropriate, including with the proposed National Communicable Diseases Framework and the National Sexual Health Strategy.

Optimal implementation of the *National Hepatitis C Strategy* also demands that, following development or review, State and Territory hepatitis C strategies and action plans are consistent with the objectives and priority areas identified in this Strategy.

Initiatives implemented under this Strategy rely and build on the underlying health system infrastructure and capacity. Coordination across related initiatives will increase our ability to draw on this infrastructure and capacity and sustain the population health effort directed towards hepatitis C. Coordination with other national population health initiatives also ensures that proven successes in related areas serve as platforms for learning and continuous improvement in the national response to hepatitis C.

Coordination across the community and other non-government sectors is also warranted, to maximise opportunities for health protection and promotion interventions and secure optimal implementation of the *National Hepatitis C Strategy*.

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

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# 3 Reducing hepatitis C transmission in the community

A central element of the *National Hepatitis C Strategy* will be continuation of the services and interventions that have characterised Australia's response to blood borne viruses. Despite the established prevention programs, the continuing high rate of new infections in Australia emphasises the need for increased efforts to reduce risk behaviours and an expansion of proven health promotion interventions, as well as investigation of other innovative interventions and multi-faceted approaches to reduce transmission of hepatitis C in the Australian community.

Approximately 90 per cent of all new hepatitis C infections arise from injecting drug use (ANCARD Hepatitis C Sub-committee 1998). Obviously, individuals can play an important part in reducing the transmission of hepatitis C—for themselves and in the broader community—by avoiding risk behaviour such as injecting drug use. This Strategy supports demand reduction interventions such as education, counselling and other drug treatment programs implemented under the *National Drug Strategic Framework* for the central role they play in reducing the prevalence of this high risk behaviour and the consequent risk of hepatitis C infection. To complement efforts under the Framework, interventions developed and implemented under this Strategy to reduce new infections will focus on reducing the harm associated with injecting drug use.

Since the vast majority of new hepatitis C infections arise from injecting drug use, the importance of adequate needle and syringe programs for preventing hepatitis C transmission is emphasised, as is the need for continued support for evidence-based interventions.

## 3.1 Objectives

- To reduce transmission of hepatitis C infection.
- To raise awareness of hepatitis C transmission risks and improve knowledge and skills for sustaining preventive practices.

## 3.2 Guiding principles

- The principle of harm reduction has primacy in the development and implementation of interventions to reduce hepatitis C transmission.
- Transmission of hepatitis C is preventable providing people have adequate and equitable access to information, specific education and sterile equipment.
- Each person must accept responsibility for taking action to avoid becoming infected and for preventing further transmission of the virus.
- To optimise access to prevention and education interventions for people at risk of hepatitis C infection, initiatives to reduce transmission must take account of cultural and linguistic backgrounds, gender, age, standards of literacy, disability, geographical location, and economic and financial factors.
- Prevention and education initiatives need to accept and respect existing social and cultural practices within target populations and be delivered in a non-judgmental, non-discriminatory manner.
- The involvement of people affected by hepatitis C in reducing hepatitis C transmission is fundamental to prevention work.
- Health promotion activities for specific communities are best developed and delivered by those communities through peer based initiatives in partnership with governments, health professionals and researchers.
- The best available evidence must underpin education and prevention interventions.
- Adequate surveillance and monitoring mechanisms are essential for identifying population groups at risk, guiding prevention interventions, and evaluating success.
- Materials designed to reduce transmission of hepatitis C must have maximum effect on risk-related behaviours in specific contexts. The use of explicit images and language in education programs is warranted if it is necessary for effective communication and if it is culturally relevant and accurately targeted.

## 3.3 Risk factors and contexts

Specific social, cultural and occupational practices that expose a person to the blood or blood products of another person can lead to hepatitis C transmission. Such practices involve the use of equipment that is not sterile, such as the sharing or re-using of any item of equipment that has already been used:

- for the purpose of injecting
- for the purpose of skin penetration, including for body piercing
- for the purpose of tattooing
- in health care settings
- in other industries where a person may be exposed to another person's blood.

The risk of transmission depends on the context in which such practices occur, as well as other contributing factors.

### 3.3.1 Sharing and re-using injecting equipment

Any sharing or re-using of injecting equipment that involves blood-to-blood contact is a very high risk factor for hepatitis C infection. The risk of transmission occurring in this way extends beyond needles and syringes to spoons, water, tourniquets and swabs and contact with anything else (such as hands) that might have traces of blood on it.

Both sharing and re-using injecting equipment are risk behaviours associated with particular cultural and social determinants. The meanings and rules of sharing and re-using—including the items shared and the social circles where the sharing takes place—will vary across communities and social contexts. Furthermore, the circumstances in which injecting, sharing or re-using takes place (such as street use) affect the risk of blood-to-blood contact. The risks of sharing or re-using injecting equipment are also greater if the availability of sterile injecting equipment is limited.

### 3.3.2 Re-infection

As noted, previous infection with one strain, or genotype, of hepatitis C does not protect against re-infection with the same or a different strain of the virus, irrespective of whether a chronic illness subsequently develops or the infection is cleared. Prevention efforts must also target people with hepatitis C who continue to engage in risk behaviours, to prevent re-infection and its associated accelerated morbidity.

These prevention efforts should also focus on providing people with hepatitis C with the skills and knowledge to prevent further transmission of the virus.

### 3.3.3 Rural, regional and remote areas

Gaining access to education, skills and the necessary equipment for maintaining preventive practices is often difficult in rural, regional and remote areas. Community sentiment, a lack of confidentiality and judgmental attitudes by some health care workers—coupled with limited access to sterile injecting equipment and other services—can severely hinder hepatitis C prevention in these areas.

Transient and itinerant populations and workforces in remote or isolated locations, such as workers in mining and fishing and some agricultural industries, face particular problems in gaining access to the means of preventing hepatitis C transmission.

In many regions of Australia, Indigenous communities are quite mobile and therefore providing accessible and appropriate services can be problematic.

### 3.3.4 Custodial settings

As noted, a history of incarceration is a potent risk factor for hepatitis C transmission because of the high prevalence of hepatitis C among custodial populations.

There are over 20 000 inmates of custodial institutions at any time in Australia and the average term of imprisonment is 10 months. Given the large number of people entering and leaving the corrections system each year, custodial settings pose a serious ‘incubator’ threat both to inmates and

custodial staff and, upon inmates' release, to the broader Australian community.

Within custodial settings access to education, the means of preventing transmission and infection control is severely limited. There are also restrictions on the distribution of a number of personal hygiene items such as razors and scissors, and infection control within prison hairdressing facilities needs improvement. Sterile tattooing and injecting equipment is not available, and the means to clean such equipment is limited. As a result, sharing and re-using of unsterile equipment is common. Acts of violence involving blood-to-blood contact are also common and pose an additional threat to all within these settings.

The high level of Indigenous peoples in custodial settings is a matter that places this population at particular risk of hepatitis C infection.

As well, the over-representation of people with limited literacy in custodial settings poses a further challenge for the provision of accessible prevention and education interventions.

### **3.3.5 Mental health**

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

### **3.3.6 Occupational exposure**

Specific occupations—such as health care workers (including paramedics and needle and syringe program workers), dental workers, cleaning and waste-management workers, hairdressers and beauticians, tattooists and body-piercing practitioners, personal carers, and food preparation workers—may pose risks for hepatitis C transmission. This risk is dependent on the likelihood of becoming infected after contact with blood from an infected

source, the frequency of blood contact, the ability of the virus to survive outside the body, and the prevalence of hepatitis C infection within the general population.

Improved application of occupational health and safety policies and programs across these sectors will reduce the risk of accidental exposure to hepatitis C infection, as will interventions aimed at reducing the prevalence of hepatitis C in the general community.

### **3.3.7 Exposure in sport**

Although there have been no documented cases of hepatitis C transmission arising from participation in sporting activities, a theoretical (albeit very low) risk does exist. The risk is, however, generally limited to sports involving high levels of body contact or where impact regularly occurs—such as boxing, wrestling, martial arts and some football codes—and where a participant may be exposed to blood-to-blood contact while wearing little or no protective clothing.

### **3.3.8 Non-occupational exposure to discarded injecting equipment**

There are no documented cases in the world of hepatitis C transmission from accidental non-occupational exposure, such as contact with inappropriately discarded needles and syringes. In addition, a range of strategies have been developed and implemented to promote safe disposal of used injecting equipment.

The risk of hepatitis C transmission through non-occupational exposure is often exaggerated. In reality this risk is low. There is, however, continued community concern about the reported risks associated with exposures of this kind: the media are encouraged to frame their reports in a responsible manner, having regard to the actual risks of transmission.

### **3.3.9 Securing the blood supply**

Australia responded promptly when the hepatitis C virus was identified as a risk to the safety of the blood supply by introducing screening for hepatitis C as soon as an antibody test became available in 1990.

Following the 1999 Australian Health Ministers Conference, nucleic acid testing, the latest testing technology, was approved for introduction from June 2000 as the new standard for screening fresh blood products for hepatitis C and HIV. As noted, this new technology reduces the ‘window period’ for detecting the virus to 23 days on average, by which time it is thought that the viral load will be too low for transmission. In addition, the Therapeutic Goods Administration is responsible for developing standards and requirements for blood and blood components and will audit blood banks to ensure compliance with the Code of Good Manufacturing Practice for Human Blood and Tissues. These initiatives will ensure that the Australian blood-banking system operates in accordance with best international practice. The risk of hepatitis C transmission through transfusions is now considered very low, although continued vigilance is necessary to maintain the security of Australia’s blood supply.

### 3.3.10 Other constraints on access

Poverty, unemployment, limited education or low literacy levels, and inadequate housing can restrict access to preventive interventions and compromise perceptions of risk and access to the means for health maintenance. These factors can also have greater prominence in a person’s life than hepatitis C and consequently limit access to the means of prevention.

The risk of hepatitis C transmission through drug use is also influenced by factors such as the method of administering drugs, the pattern and frequency of drug use, trends in the drug market, the circumstances of people using the drug, and the pharmacology of the drug.

Further, the unintended consequences of the law and its enforcement can compromise prevention efforts. For example, strict policing practices in the vicinity of needle and syringe programs can adversely affect the programs’ operation. To maximise the programs’ accessibility to their intended clients, law enforcement agencies throughout Australia have developed complementary operational guidelines to support the continued effectiveness of these programs.

## 3.4 Challenges

- To monitor and respond to changing patterns in risk behaviours and their contexts.
- To involve all levels of government in promoting guidelines and practices that facilitate access to resources designed to reduce hepatitis C transmission.
- To maintain non-partisan support for population health initiatives, such as needle and syringe programs, that are proven in reducing transmission of hepatitis C.
- To support innovative approaches that enhance educational opportunities for reducing hepatitis C transmission.
- For people with or at risk of hepatitis C, to broaden access to the means of preventing transmission and re-infection.
- To enhance the capacity of and support peer educators and peer based drug user groups to reduce the transmission of hepatitis C in the context of holistic health and wellbeing.
- To develop and implement a best-practice framework to guide hepatitis C education and prevention.
- To augment the skills of workers in health care services for people with or at risk of hepatitis C.
- To encourage health care service providers, including pharmacists, to participate in hepatitis C education and prevention, in partnership with affected communities.
- To promote nationally consistent occupational health and safety standards for the health care, tattooing, skin-penetration and other industries with elevated risks of exposure.
- To promote equitable access and standards of hepatitis C prevention and education in rural, remote and regional areas.
- To support the implementation of nationally consistent standards for hepatitis C education and prevention in custodial settings.
- To promote multi-disciplinary research across the partnership, to guide best practice in hepatitis C prevention.
- To promote the development of legal environments that support prevention of hepatitis C transmission.



## 3.5 Opportunities

### 3.5.1 The National HIV/AIDS Strategy

- To support efforts under the *National HIV/AIDS Strategy* to develop an ‘enabling environment’ and promote the removal of legal impediments to the prevention of transmission of blood borne viruses.

### 3.5.2 The National Drug Strategic Framework

- To support efforts to reduce the prevalence of risk behaviours such as injecting drug use.
- To support the development of effective, accessible and attractive treatments for drug dependency. In developing these treatments, account should be taken of possible interactions between treatments for drug dependency and hepatitis C infection.
- To support initiatives to promote the diversion of people who use illicit drugs away from incarceration into alternative, non-custodial options.
- To promote the expansion and availability of treatments for drug dependency within custodial settings.
- To support law enforcement agencies in their commitment to implement operational guidelines that complement the effective operation of needle and syringe programs and other harm reduction initiatives.

### 3.5.3 The Australian Hepatitis C Surveillance Strategy

- To support the *Australian Hepatitis C Surveillance Strategy* in developing nationally consistent protocols for notifications and data collection to improve our understanding of the epidemiology and natural history of hepatitis C and in monitoring and responding to changing patterns in risk behaviours and their contexts.
- To foster and maintain nationally consistent surveillance of occupational exposure in health care settings.

### **3.5.4 The National Indigenous Australians' Sexual Health Strategy**

- To increase use of the population health networks that exist for Aboriginal and Torres Strait Islander people and establish appropriate partnerships across different sectors.
- To support the development of innovative responses that are culturally appropriate to the specific circumstances of Aboriginal and Torres Strait Islander people.

### **3.5.5 The National Mental Health Strategy**

- To support the participation of providers of mental health services in developing and implementing hepatitis C education and prevention interventions.
- To establish links with the Australian Transcultural Mental Health Network to help target people from culturally and linguistically diverse backgrounds who may be at particular risk of hepatitis C infection as a result of injecting drug use.

### **3.5.6 Healthy Horizons: a framework for improving the health of rural, regional and remote Australians**

- To support the provision of hepatitis C education and prevention interventions for people at risk of infection and living in rural, regional and remote areas of Australia.

## 4 Treatment of hepatitis C infection

Treatment options for hepatitis C infection have greatly improved in recent years. By using combination therapy—interferon and ribavirin—it is now possible to offer sustained improvement in liver function, as well as viral suppression, in up to 40 per cent of people with hepatitis C and a considerably higher proportion of infected people with a favourable genotype (2,3) and low viral load (Sievert 2000). This significant improvement in our ability to suppress or even eradicate certain subtypes of the virus in particular individuals elevates the place of treatment in the list of strategies for dealing with hepatitis C. Although health promotion for people with hepatitis C remains the best strategy for preventing transmission and managing the impacts of chronic infection, improving treatments and widening their availability, as well as identifying the groups that are most suitable for treatment, are now central to the response to hepatitis C infection in Australia.

A unique feature of the treatment landscape in Australia is the variety of genotypes, which is a reflection of the cultural diversity in the community and is related to where and how people are infected. This genotype diversity affects responses to treatments and possibly the natural history of infection.

The *Strategy for the Detection and Management of Hepatitis C*, released by the National Health and Medical Research Council in March 1997, provided information on the characteristics and transmission of hepatitis C, screening and surveillance, laboratory testing, clinical indications for testing, clinical protocols, and guidelines for general practitioners. Given the rapid changes in our understanding of the nature of hepatitis C infection and the development of new treatments, a major initiative of this *National Hepatitis C Strategy* will be to provide a framework for the continuing improvement and application of treatments and best-practice models of care.

## 4.1 Objective

- To maximise the health and wellbeing of people with hepatitis C.

## 4.2 Guiding principles

- People with hepatitis C should have equitable access to the full range of treatments.
- People with hepatitis C should be involved in the planning, implementation and evaluation of treatment programs.
- Accessible and culturally appropriate information and education about treatment options must be provided, so that people with hepatitis C can make informed choices.
- The development of new and improved treatments requires continuing, sustainable basic, virological and clinical research.

## 4.3 Contexts

### 4.3.1 The potential demand for treatment

As noted, at the end of 1997 there were approximately 134 000 people with chronic hepatitis C infection in Australia. Of these, less than 3000 people have so far sought clinical treatment for their illness; the vast majority are yet to seek treatment or care and support. The high rate of new infections in Australia—approximately 11 000 each year—also contributes to the pool of potential demand for treatment.

### 4.3.2 Barriers to clinical treatment

Three principal barriers deter people with hepatitis C from seeking treatment:

- the limited efficacy of treatments for hepatitis C infection
- the toxicity and complex administration of these treatments

- the priority that seeking treatment may have for people with hepatitis C relative to other health needs, especially if their hepatitis C infection remains asymptomatic or manageable.

Added to these considerations, significant numbers of those suspected to have been infected with the hepatitis C virus remain undiagnosed, and largely asymptomatic, and have not yet sought testing or treatment.

### 4.3.3 Testing

Testing is a primary tool in diagnosing infection and assessing the prognosis for people with chronic hepatitis C. Treatment decisions are based on diagnostic and other qualitative testing, such as viral load and genotype testing, which are also emerging as important prognostic tools.

General practitioners and other primary health care providers have a vital role—both for routine patients and for participants in clinical trials—in performing diagnostic testing as well as conducting adequate pre-test discussions and offering post-test counselling. They also have an important role in providing information, support and referral to people with hepatitis C.

A nationally agreed policy for hepatitis C testing will be developed, incorporating guidelines for pre-test discussion and post-test counselling. This policy will also establish nationally consistent protocols for testing (diagnostic screening for antibodies, PCR testing, and viral-load and genotype tests), test kit classification systems and quality assurance. The policy should help to refine our understanding of the epidemiology (including the natural history) of hepatitis C, aid service planning and provide an opportunity for health promotion interventions.

### 4.3.4 Access to treatment

Access to treatment for hepatitis C infection is limited for a range of people with hepatitis C, often because of a combination of social, cultural, economic or geographic barriers and service capacity.

Interferon is available through the Highly Specialised Drugs Program, which is delivered under section 100 of the *National Health Act*. Among the criteria currently governing the availability of this treatment are that interferon is to be prescribed through tertiary treatment centres only, that the prescribing facility must provide a nurse educator/counsellor, that the facility must have

an established outpatient liver clinic with the capacity to conduct safe liver biopsies, and that patients must have 24-hour access to medical advice. These requirements may have a number of consequences, including:

- increasing waiting times between referral and gaining access to treatment services
- increasing the pressure on public hospital resources
- reducing access for people seeking treatment outside urban centres.

It is necessary to explore options that will support broader access to treatments and specialist advice, while not compromising patient care and monitoring and the clinical need for appropriate use of these medicines. Trials of coordinated-care arrangements are under way in a number of regions throughout Australia. Evaluating these trials, further exploring models for shared-care arrangements between primary health care providers and specialists, and improving the shared-care arrangements will be a key to augmenting capacity and improving access. Other options might include improving the targeting of treatment programs—in particular, defining those groups most suitable for treatment—to provide for greater effectiveness.

As noted, the prevalence of hepatitis C among inmates of custodial settings is high. Being incarcerated should not be a barrier to obtaining treatment for hepatitis C, and such settings provide ample opportunity for health maintenance and treatment interventions. Although some treatment programs have been established successfully in custodial environments, limited access to hepatitis C treatments for inmates remains a problem.

The information needs of people contemplating or participating in treatment can be substantial. To enable people with hepatitis C to make informed choices about treatment, information about treatment options should be provided in accessible formats and should reflect the diverse needs of people with hepatitis C.

Many people with hepatitis C who were born outside Australia acquired their infection through unsterile medical procedures in their country of birth. Large numbers of these people now have advanced liver disease and have particular information needs in relation to treatment and health maintenance arising from their non-English speaking background.

### 4.3.5 Complementary and alternative therapies

The use of complementary and alternative therapies is widespread among people with hepatitis C. The limited body of research into complementary therapies shows that such therapies have limited effect on viral activity but more success in alleviating the symptoms of infection. There is a need for further research into and more information about the impact of these therapies on hepatitis C infection and liver function generally.

## 4.4 Challenges

- To ensure equivalent access for people with hepatitis C seeking treatment, regardless of their social, cultural, economic or geographic circumstances.
- To provide the best treatments available, supported by patient education and counselling, to reduce current and long-term morbidity, particularly for people with hepatitis C who are most likely to progress to advanced liver disease.
- To expand knowledge, understanding and choices in relation to hepatitis C treatments.
- To review, consider and trial models of providing treatment and care, including shared-care arrangements and non-hospital based liver clinics, that would improve access to treatments and specialist advice.
- To develop and trial models of shared care that integrate primary and secondary health care services for people with hepatitis C.
- To increase access to specialised hepatitis C treatments by extending prescribing rights beyond hospital-based clinics.
- To provide continuing training and education on developments in clinical treatment to health care workers dealing with people who have hepatitis C.
- To support increased access for people with hepatitis C in custodial settings who are seeking treatment and to provide accessible information about hepatitis C treatments.
- To ensure that established regulatory processes remain responsive to new developments in therapy, especially in relation to prompt assessment of new technologies and new therapeutic agents.

- To develop and implement a nationally accepted testing policy for hepatitis C.
- To provide treatment information that is accessible as well as culturally and linguistically appropriate.
- To develop a broader range of treatments for hepatitis C infection.
- To improve our knowledge and understanding of the role of complementary and alternative therapies in treating hepatitis C infection and in alleviating the symptoms of infection.
- To support comprehensive peer education programs to encourage people with hepatitis C who inject drugs to engage with the primary health care sector.
- To investigate the development of post-exposure prophylactic therapies and promote access to these therapies for people with acute infection.
- To investigate the impacts of multiple hepatitis C infections on morbidity and mortality and promote the development of suitable therapies.
- To support international cooperation in the field of hepatitis C basic, virological and clinical research because of the research's potential to develop more effective treatments and possible vaccines.

## 4.5 Opportunities

### 4.5.1 The National Mental Health Strategy

- To establish links with mental health service providers and so support the development of hepatitis C treatment-support programs, to take account of the psychological side effects of both hepatitis C infection and current treatment regimes and ensure that such programs are accessible to the diversity of people with hepatitis C undergoing treatment. Appropriate treatment-support programs are vital for people with co-morbidity of mental illness, especially those in custodial settings and psychiatric institutions.
- To support the education of mental health service providers on the risk factors associated with hepatitis C infection and consequent health care needs.



#### 4.5.2 Healthy Horizons: a framework for improving the health of rural, regional and remote Australians

- To facilitate links with services established under the Regional Health Services Program to improve access to hepatitis C treatments for people living in rural, regional and remote areas of Australia.

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

In this *National Hepatitis C Strategy*, health maintenance, care and support matters are separated from clinical treatment of hepatitis C infection in recognition of the limited number of people with hepatitis C undertaking treatment. This is largely a consequence of the limited accessibility of treatments and treatment providers and the barriers to treatment discussed in Chapter 4.

On its own, clinical treatment for hepatitis C infection and associated liver disease is insufficient to ensure health and wellbeing. Symptoms of hepatitis C—such as fatigue, nausea, depression, and headaches—may not be brought to the attention of specialist hepatitis C clinical services. Moreover, a considerable range of factors that affect the health and wellbeing of people with hepatitis C do not necessarily come within the scope of specialist hepatitis C clinical services.

For many people with hepatitis C the primary sources of care and support are their personal networks—partners, family, friends, peers and colleagues. These people are also affected by hepatitis C and are included in the scope of the care and support needs expressed in this Strategy.

Among the factors that affect the health and wellbeing of people with hepatitis C are the following:

- anxiety and stress associated with having a chronic condition such as hepatitis C
- fatigue, nausea and other symptoms of chronic hepatitis C infection
- treatment side effects such as depression and nausea
- nutrition is important for maintaining health and wellbeing, including for people with hepatitis C
- dental care—some dental conditions can occur more frequently and more severely among people with chronic hepatitis C

- alcohol—there is emerging evidence of a clear relationship between alcohol consumption and accelerated development of severe liver disease such as cirrhosis
- co-infection with any of HIV, hepatitis A, hepatitis B and other hepatitis C genotypes, which can contribute to a poorer prognosis, especially if combined with other medical conditions
- housing, adequate income and employment—hepatitis C illness can force some people out of the workforce, either temporarily or permanently, and can contribute to or exacerbate poverty
- fear of discrimination, which can impair a person’s ability or motivation to seek out and make use of services.

This Strategy seeks to ensure that the health maintenance, care and support needs of people with hepatitis C are met. This chapter complements Chapter 4 and focuses the attention of service planners and providers on broad needs that may or may not be directly related to treatment. There may be some overlap in the matters discussed here and in Chapter 4; for example, in the discussion of dealing with the side effects of treatment.

## 5.1 Objectives

- To reduce the personal and social impacts of hepatitis C infection.
- To increase the knowledge and skills of people affected by hepatitis C to help them maintain their health and quality of life.
- To ensure equitable access to health maintenance, care and support services for all people affected by hepatitis C.

## 5.2 Guiding principles

- All people affected by hepatitis C should have the same opportunities for care and support, irrespective of the means of infection.
- The planning, delivery and evaluation of all policy and activity connected with health maintenance, care and support should involve people affected by hepatitis C.

- All people affected by hepatitis C should have equitable access to information, education and care and support services that help them maintain their health and wellbeing and are responsive to their individual needs.
- Health maintenance, care and support activities must be guided by the best available evidence.

## 5.3 Risk factors and contexts

A number of factors can pose a threat to the wellbeing of people affected by hepatitis C or reduce the effectiveness of interventions designed to improve their health. These factors can be individual, physical or psychological, or they can be a feature of the environment.

### 5.3.1 Physical and psychological factors

A variety of physical conditions can affect the health and wellbeing of people with hepatitis C. For example, co-infection with HIV, hepatitis A, hepatitis B or other strains of the hepatitis C virus exacerbates symptoms and leads to a bleaker prognosis. Consumption of alcohol in harmful or hazardous quantities will also predispose a person with hepatitis C to advanced liver disease.

There is considerable evidence linking chronic illness with the development of depression and other psychiatric disorders (ABS 1996). Like other chronic conditions, hepatitis C places additional stress on a person's emotional wellbeing. Pre-existing conditions such as depression and anxiety disorders will increase the disability experienced by people with hepatitis C and further complicate the type of care and support services they need. Preventing and treating depression in people with hepatitis C—whether the depression was pre-existing or is linked to hepatitis C infection—is likely to have a synergistic effect through reducing the compounding impacts of mental and physical conditions. Current treatments can also produce serious psychological side effects, such as depression, for many people. Care and support providers need to be mindful of the range of potential side effects of treatments.

## 5.3.2 Rural, regional and remote areas

The limited availability of services in rural, regional and remote areas of Australia affects the care and support of people affected by hepatitis C.

## 5.3.3 Custodial settings

As noted, the prevalence of hepatitis C among people in custodial settings is high. These settings are stressful, crowded and often violent, and, generally speaking, inmates with hepatitis C do not have access to health education and maintenance and care and support services equivalent to the access enjoyed by people in the wider community. Health authorities operating in custodial settings have a duty of care for people in these settings, and clear opportunities exist for positive application of this principle to inmates with hepatitis C.

## 5.3.4 Diversity of service needs

People affected by hepatitis C come from all parts of the Australian community and consequently make use of a wide range of services for information, advice, support, testing and treatment. Among the service providers are general practitioners, hepatitis C councils, peer based drug user groups, haemophilia foundations, liver clinics, health services in custodial settings, needle and syringe programs, community health centres, haemophilia treatment centres, drug-dependency treatment centres (including methadone clinics and detoxification units), mental health services, Aboriginal and Torres Strait Islander primary health care services, and specialist health services for people from culturally and linguistically diverse backgrounds.

The type of service or services someone makes use of for health education and maintenance and care and support is strongly influenced by factors such as geographical location, cultural and linguistic background, and financial limitations. Health care service providers must be capable of providing appropriate health education, care and support for people affected by hepatitis C. To achieve this, staff in these services should receive adequate training and education, in both hepatitis C related matters and non-judgmental service provision.

## 5.4 Challenges

- To develop, trial and implement models of case management that contribute to improved service delivery and are individually and collectively more responsive to clients' needs, resulting in improved health outcomes and wellbeing for people affected by hepatitis C.
- To support comprehensive peer education programs to help people with hepatitis C who inject drugs engage with the primary health care sector and so increase their opportunities to protect and maintain their health.
- To ensure that health education and care and support services have the continuing resources and training needed to provide high quality, evidence-based interventions.
- To ensure that health education and maintenance messages are based on the best available evidence.
- To develop health education and care and support services that are accessible and culturally appropriate to the diversity of people affected by hepatitis C.
- To promote and increase the accessibility of vaccination against hepatitis A and hepatitis B for people with hepatitis C who are not immune to these viruses.
- To increase access to appropriate health education and care and support services for people with hepatitis C in custodial settings. This involves education of custodial staff, provision for health monitoring, vaccination against hepatitis A and hepatitis B, and provision of suitable diets.
- To provide appropriate health care services with a continuum of care in regional, rural and remote Australia through developing and testing innovative service delivery models.
- To provide access to information, education and support for both professional and non-professional carers.
- To incorporate information on hepatitis C health education and care and support in clinical training and education programs for health care workers.
- To promote training and education of dental health care workers to ensure that they understand the specific dental health needs of people with hepatitis C, infection control procedures and non-discriminatory work practices.

## 5.5 Opportunities

### 5.5.1 The National HIV/AIDS Strategy

- To link the health education and maintenance and care and support needs of people with hepatitis C in custodial settings with activities conducted under the *National HIV/AIDS Strategy*.

### 5.5.2 The National Drug Strategic Framework

- To support efforts under the *National Drug Strategic Framework* to reduce the alcohol intake of people with hepatitis C.

### 5.5.3 The Enhanced Primary Care initiative

New Medicare Benefits Schedule items enabling general practitioners to undertake or participate in care planning and case conferencing for people with chronic conditions and multi-disciplinary care needs were introduced in November 1999 as part of the Enhanced Primary Care initiative. The availability of these items will enable a closer linkage between general practitioners and other health care providers in meeting the care and support needs of people affected by hepatitis C.

- To provide further support for people affected by hepatitis C through improved integration with other primary health care initiatives, such as coordinated-care and self-management programs, which aim to help people with chronic conditions manage their illness and maintain their health.

### 5.5.4 The National Mental Health Strategy

- To establish links with mental health service providers to encourage the development of appropriate care and support programs for people affected by hepatitis C and to deal with the psychological side effects of both hepatitis C infection and current treatment regimes.



### **5.5.5 Healthy Horizons: a framework for improving the health of rural, regional and remote Australians**

- To establish links with services established under the Regional Health Services Program to improve access to care and support programs for people affected by hepatitis C who are living in rural, regional and remote areas of Australia.

### **5.5.6 The National Indigenous Australians' Sexual Health Strategy**

- To establish links with population health networks that exist for the provision of culturally appropriate health education and care and support for Aboriginal and Torres Strait Islander people.

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# 6 Preventing discrimination and reducing stigma and isolation

Ignorance about hepatitis C, its means of transmission, and the degree of infectiousness has resulted in high levels of community anxiety and misconception about the virus. This anxiety is often directed at people with, or assumed to carry, the virus. The high prevalence of hepatitis C among people with a history of injecting drug use, together with community perceptions of people who inject drugs, have added to the fear of this virus and attached stigma to those affected by it. This stigma may cause people with or at risk of hepatitis C to avoid testing and deny or conceal their health status.

People with hepatitis C who choose to disclose their status may be subjected to further and more overt discrimination, with an increased likelihood of stigmatisation and social isolation. This affects not only relationships with friends and family, employers and colleagues but also contact with the services intended to provide health maintenance and support.

To help people affected by hepatitis C initiate action to reduce the likelihood of transmission and maximise their health and wellbeing, it is necessary that health promotion efforts under this *National Hepatitis C Strategy* address the discriminatory practices directed at these people. Dismantling discrimination, isolation and stigma is critical to achieving the aims of the Strategy.

## 6.1 Objectives

- To prevent discrimination and to reduce the stigma and isolation experienced by people affected by hepatitis C.
- To promote the rights and enhance the ability of people affected by hepatitis C to participate in society and to remove barriers to the exercising of those rights.

## 6.2 Guiding principles

- Policies designed to eliminate patterns of discrimination, isolation and stigma experienced by people affected by hepatitis C must underlie activity at all levels of the partnership.
- People affected by hepatitis C, regardless of the means of transmission, should have the same access to high quality, compassionate health care as other members of the community.
- A client focus and the principles of access, equity, participation and equality for all individuals and affected communities are integral to Australia's response to hepatitis C.
- It is essential that people affected by hepatitis C participate in the development of resources and services that aim to improve their health status and reduce their isolation.

## 6.3 Contexts

People with or at risk of hepatitis C come from diverse backgrounds: ethnicity, race, education, occupation, age, gender and social status do not act as barriers to transmission. Consequently, a wide range of contexts influence the needs of people affected by hepatitis C. These contexts must form part of the framework in which efforts to dismantle discrimination, stigma and isolation occur; some of these contexts are discussed in this section.

### 6.3.1 Rural, regional and remote communities

In small communities disclosure of an individual's health status can easily lead to public identification. Any consequent discrimination can limit a person's participation in the community, limit their employment opportunities, and affect the provision of goods and services, including health care. Experiences of social isolation can be exacerbated by the lack of specific hepatitis C health care services or advocacy and support groups in rural, regional and remote areas.

### 6.3.2 Aboriginal and Torres Strait Islander people

Discrimination, stigma and disadvantage experienced by Aboriginal and Torres Strait Islander people affect their access to and the provision of primary health care services. These inherent experiences also complicate efforts to deal with hepatitis C in Indigenous communities.

For Aboriginal and Torres Strait Islander people with hepatitis C, discrimination and stigma can also come from within their own communities. Where primary health care services are administered by community members, identification as a person with hepatitis C (and the subsequent association with injecting drug use) can inhibit access to or the provision of health care and social support services offered by that community.

Community mores and cultural interpretations of shame can result in Aboriginal and Torres Strait Islander communities denying the existence of risk practices associated with hepatitis C transmission. These practices can range from injecting drug use to other practices that involve blood-to-blood contact, or they can be the result of a confluence of factors, such as cultures of sharing and their effect on injecting drug use.

Reducing the discrimination, stigma and isolation experienced by Aboriginal and Torres Strait Islander people affected by hepatitis C requires initiatives that take into account these cultural determinants. This can occur only if Aboriginal and Torres Strait Islander people are afforded the same opportunities to participate in the development of these initiatives and the same levels of access to primary health care services as are proposed for the broader community.

### 6.3.3 Culturally and linguistically diverse communities

Hepatitis C affects many ethnic groups in Australia. Particular cultural practices and cultural determinants, such as belief systems and languages, can give rise to particular experiences of discrimination, stigma and isolation. These experiences may then hinder efforts to tackle hepatitis C in these communities.

A desire by some community leaders to maintain respectability and confidentiality in their communities may result in reluctance to admit to the presence of illegal activities or risk practices in that community. This can

lead to rejection of community members who are seen (or perceived) to be engaging in such practices. Consequently, individuals with or at risk of hepatitis C may be more difficult to identify and reach with interventions and support services.

Some groups or individuals have limited contact with the health care system as a result of real or perceived linguistic and cultural inaccessibility. Linguistically and culturally appropriate service provision is needed to make the health care system more accessible and to ensure that information intended to reduce transmission and promote health maintenance is appropriate to a community's needs.

### 6.3.4 Injecting drug use

Evaluations of successive national HIV/AIDS strategies have found that, when provided with information and resources, people who inject drugs will adopt improved health-protection practices (see, for example, Department of Human Services and Health 1995). The association of hepatitis C with injecting drug use is reported as the single most common cause of discrimination, stigma and isolation experienced by people affected by hepatitis C.

To reduce this impact on people affected by hepatitis C, regardless of how someone has contracted the virus, it is necessary to confront a number of difficulties, among them the following:

- stereotyping of people who inject drugs
- the association of injecting drug use with a disregard for personal health
- fear
- difficulty in understanding why people use drugs.

This Strategy will establish links with the *National Drug Strategic Framework* to enhance community understanding of the variety of injecting drug use patterns, practices and subgroups in the community, to reduce discrimination, stigmatisation and isolation.

### 6.3.5 Workers in health care settings

Although the majority of health care providers fulfil their duties in a professional and non-discriminatory manner, it must be noted that workers in

health care settings are repeatedly cited as a source of discrimination against people affected by hepatitis C. Regrettably, this discrimination is often initiated at the point of clinical diagnosis. Discrimination may be extreme, as in the case of discouraging or refusing service, or it may be less direct, in the form of judgments made on the basis of known (or imputed) current or past behaviours. The experience of such discrimination may result in reduced contact with health care services, denying people the opportunity to maximise their health. Education and training of health care workers is needed, to reduce discrimination and promote non-judgmental behaviour towards people affected by hepatitis C.

The prevalence of hepatitis C among health care workers is no higher than that in the general population. In spite of this, though, health care workers themselves also experience stigma, isolation and prejudicial behaviour, including inappropriate responses from the health system when (potentially) exposed to a blood borne virus such as hepatitis C and HIV via an accidental needlestick injury or some other form of exposure. This experience, or witnessing a colleague's experience, may then deter health care workers from reporting possible exposures to blood borne viruses because of the potential impact on their employability.

There is a need to improve practices generally in health care settings, in management practices for people with hepatitis C seeking treatment and care and for health care workers themselves, who may be exposed through occupational hazards. The universal application of Standard Precautions for infection control would help eliminate prejudicial behaviour in health care settings.

### **6.3.6 People receiving blood products**

The impact of hepatitis C for people who became infected with the virus through blood products, including people with haemophilia, is significant. People with haemophilia report discrimination prompted by an assumption that they are infected with hepatitis C or other blood borne viruses such as HIV. This compounds the stigma they experience as a result of their existing medical condition. Given the history of transmission of hepatitis C through blood products, it is important that this community be involved in responding to discrimination.

### 6.3.7 Co-infection

Co-infection of hepatitis C with other blood borne viruses such as hepatitis B, HIV or other strains of hepatitis C subjects people to complex health maintenance needs and the added stigma of co-infection or multiple infection. Co-infection is an exceedingly complex context in which social isolation and stigma and the psychosocial impacts of the physical conditions in question need to be fully taken into account.

### 6.3.8 Anti-discrimination legislation

For the purposes of anti-discrimination legislation, hepatitis C infection is regarded as a disability in all Australian jurisdictions. Seeking redress under anti-discrimination legislation poses a series of challenges for a potential complainant, who is confronted by barriers such as the lack of enforceable remedies, delays, and the financial disincentives associated with proceedings.

Despite these barriers, more effective use of existing anti-discrimination laws may have a particularly beneficial effect in drawing attention to hepatitis C related discrimination and its impacts.

## 6.4 Challenges

- To establish a supportive political framework at all levels of government and in all jurisdictions for the elimination of discrimination, stigma and isolation experienced by people affected by hepatitis C.
- To develop a supportive legislative framework that recognises the rights and needs of people affected by hepatitis C.
- To establish in all jurisdictions partnerships with a mandate that includes preventing discrimination and reducing stigmatisation and isolation of people affected by hepatitis C.
- To ensure that health care services are accessible to and tolerant of the individual needs and dignity of people affected by hepatitis C.
- To train and support health care workers to ensure that they do not engage in discriminatory behaviour towards people affected by hepatitis C.



- To implement Standard Precautions for infection control, universally, within health care and other skin-penetration settings.
- To promote general community education that increases blood awareness and debunks the myths surrounding hepatitis C, thereby reducing the stigma and isolation experienced by people affected by the virus.
- To implement equitable prevention, treatment and care and support systems in custodial settings for people with hepatitis C.
- To ensure that all efforts made under this Strategy to eliminate hepatitis C related discrimination take into account the full range of contexts in which that discrimination occurs.

## 6.5 Opportunities

### 6.5.1 The National Drug Strategic Framework

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

### 6.5.2 Anti-discrimination legislation

- To promote the rights and abilities of people affected by hepatitis C to seek redress through existing legal frameworks for discrimination they may experience as a result of their hepatitis C status.

### 6.5.3 The National Mental Health Strategy

- To build on efforts under the *National Mental Health Strategy* to reduce discrimination and stigma experienced by people with both a mental illness and hepatitis C.

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# 7 Roles and responsibilities

A partnership approach is fundamental to the effectiveness of the *National Hepatitis C Strategy*. Continued cooperation between and within a wide range of sectors of Australian society will be enhanced by clarification of the roles and responsibilities of the various partners.

## 7.1 The Commonwealth Government

The Commonwealth has a leadership role, and the Department of Health and Aged Care continues to be the principal Commonwealth agency responsible for promoting best practice and coordinating the national response to hepatitis C. The Population Health Division, within the Department of Health and Aged Care, has primary carriage of the National Hepatitis C Strategy. The Department has specific responsibility for the following:

- facilitating national policy formulation and coordinating hepatitis C related policies of other Commonwealth and State and Territory government agencies, in conjunction with the Australian National Council on AIDS, Hepatitis C and Related Diseases, the Commonwealth–State–Territory Government Forum, national community-based organisations, and other members of the partnership
- national leadership and coordination in health promotion, including the provision of public information on action being taken to prevent hepatitis C transmission
- administering funding to State and Territory governments and national community-based organisations
- in conjunction with all members of the partnership, developing and promoting national standards for best practice in hepatitis C health promotion, treatment, and care and support
- in conjunction with all members of the partnership, monitoring the Strategy's implementation and evaluating the Strategy and any changing trends to ensure a rapid response
- commissioning research, health promotion and policy initiatives that are best carried out on a national basis

- involvement in international cooperation
- providing secretariat and policy-support functions for national committees.

Other areas of the Department of Health and Aged Care continue to contribute to the response to the epidemic in accordance with this Strategy.

- The Therapeutic Goods Administration is responsible for regulation of medicines, blood and medical devices (including diagnostic tests) and, through the National Serology Reference Laboratory, maintaining quality in serological testing.
- The National Drug Strategy Unit has primary responsibility at the Commonwealth level for activities under the *National Drug Strategic Framework*. The Unit also ensures national coordination of policy and program management in the response to illicit drugs.
- The National Health and Medical Research Council is responsible for developing improved and consistent population health standards across Australia and for funding medical and population health research and training.
- The Office for Aboriginal and Torres Strait Islander Health is responsible for the funding of Aboriginal community controlled health and substance misuse services and aims to improve Aboriginal and Torres Strait Islander people's access to comprehensive primary health care services.

Yet other areas of the Department that are involved in funding and/or coordinating care and treatment services (including mental health and rural health services) have a responsibility to ensure that the programs they fund or manage are responsive to the needs of people affected by hepatitis C.

The Public Health Outcome Funding Agreements contribute to the national population health effort by providing broadbanded Commonwealth funding to State and Territory governments to support nominated population health strategies and programs. These Agreements aim to ensure a shared commitment to nationally agreed outcomes, as well as maintaining the commitment to implement agreed national strategies and programs through more flexible funding arrangements.

Public hospital services (delivered on site in a public hospital or as outreach services) and general practitioner services are funded through the Australian Health Care Agreements (1998 to 2003) and Medicare respectively. The

Pharmaceutical Benefits Schedule and the Pathology Services Table of the Medicare Benefits Schedule offer affordable access to hepatitis C treatments and funding for the investigation of hepatitis C infection.

The Framework Agreements for Aboriginal and Torres Strait Islander Health provide for community participation in policy development and planning and encourage the involvement of the mainstream health sector in the provision of health and related services to Indigenous Australians. Health Forums, established under every Framework Agreement, undertake regional planning, and provide a mechanism for hepatitis C initiatives targeting Aboriginal and Torres Strait Islander peoples to be progressed in partnership with Indigenous communities.

## 7.2 The Australian National Council on AIDS, Hepatitis C and Related Diseases

ANCAHRD is responsible for providing the Commonwealth Minister for Health and Aged Care with independent and expert advice on the implementation of the *National Hepatitis C Strategy* as well as the *National HIV/AIDS Strategy* and the *National Indigenous Australians' Sexual Health Strategy*. It reports annually on the implementation of these Strategies and the appropriateness of current priorities and efforts; specific performance indicators guide this reporting task.

The Minister appoints members of ANCAHRD on the basis of expertise relevant to HIV/AIDS, hepatitis C and sexual health. Committees and working groups are established as required to support ANCAHRD.

## 7.3 State and Territory governments

State and Territory governments provide leadership in the response to hepatitis C at the level of their jurisdiction. State and Territory health authorities have responsibility for, and flexibility in, program delivery. Among their particular responsibilities are the following:

- implementing the *National Hepatitis C Strategy* at the jurisdictional level

- establishing State and Territory hepatitis C strategies, including treatment and care and support plans
- establishing advisory forums with representation from all members of the partnership in their jurisdiction
- establishing public policy and legislative frameworks consistent with the aims and objectives of this Strategy
- investigating, analysing and monitoring the epidemiology of hepatitis C within their jurisdiction
- developing, funding, delivering and evaluating a range of services—such as public hospital services (delivered on site in a public hospital or as outreach services), health promotion, and care and support services provided by public and community-based organisations—that reflect the prevalence and changing needs of people affected by hepatitis C
- providing workforce infrastructure and professional development and training for workers in the hepatitis C area
- ensuring effective intersectoral cooperation between State and Territory and local government agencies
- ensuring that resources are allocated in accordance with the priority areas, having regard to the essential components expressed in this document
- measuring and reporting on the Strategy’s implementation within their jurisdiction.

## 7.4 The Commonwealth–State–Territory Government Forum

The composition and terms of reference of the Commonwealth–State–Territory Government Forum reflect the principles of both this Strategy and the *National HIV/AIDS Strategy*. The Forum is responsible for coordinating efforts under both Strategies across jurisdictions and for developing nationally consistent reporting standards.

The Forum will liaise with other organisations and committees responsible for policy areas or matters relevant to the goals of the *National Hepatitis C Strategy*. Among these organisations are the Intergovernmental Committee

on Drugs and other organisations with responsibility for national standards relating to policing, corrections and education.

The Commonwealth–State–Territory Government Forum will also continue to collaborate with ANCAHRD on all aspects of hepatitis C. This will be facilitated by cross-membership between, and community representation on, the two bodies.

## 7.5 Parliamentary liaison groups

The Commonwealth Parliamentary Liaison Group will ensure that the Commonwealth Parliament is regularly informed about the latest hepatitis C developments and will provide a non-partisan forum for policy discussion. The Group will continue to be convened by the Minister for Health and Aged Care.

State and Territory governments are encouraged to develop similar mechanisms for fostering a non-partisan, consensual approach to hepatitis C related matters.

## 7.6 Local government

The provision of services at the local and community level has become increasingly important for meeting the needs of people affected by hepatitis C. Local government involves a wide range of agencies and services that can contribute to the health and wellbeing of these people. It is well placed to respond promptly and effectively to particular local needs. Furthermore, it is responsible for urban planning and development, which affects the location and operation of health promotion initiatives such as needle and syringe programs. Local governments are in a good position to become key partners in promoting population health initiatives, and their policies should reflect the principles and priorities of the *National Hepatitis C Strategy*.

## 7.7 Research, medical, scientific and health care professionals

Australia's research and scientific communities play an essential role in reducing discrimination, reducing the transmission of hepatitis C, and providing treatment and care and support. The contribution of people working in these areas should be maximised through intersectoral cooperation at all levels. Among the organisations responsible for contributing to the response to hepatitis C are the national centres in hepatitis virology, HIV research, and alcohol and other drug research. Other bodies also contribute to the response to hepatitis C; for example, hospitals, universities and private research agencies.

Societies and associations of medical specialists and health care professionals also have an important role in the national response to hepatitis C. This sector has a central function in contributing to public and professional education about hepatitis C and developing, implementing and maintaining best-practice models of care and standards for workforce development and training to ensure high quality service provision.

## 7.8 The community sector

People affected by hepatitis C and their community organisations have a fundamental role in the development, implementation and evaluation of all aspects of Australia's strategic response to hepatitis C. The community sector brings specific expertise and values to the partnership response, and community involvement in all aspects of the response ensures recognition of the knowledge and contribution of those most affected. Partnerships between affected communities and all levels of government need to be further developed and extended.

Community organisations participate in the response in a variety of ways, among them the following:

- advocating for the interests of people affected by hepatitis C in decision making and policy formulation
- developing, delivering and evaluating policies and programs



- developing and participating in research and health promotion initiatives, including peer education and social mobilisation projects
- providing health promotion and care and support for people affected by hepatitis C
- delivering hepatitis C health promotion and primary health care services to Aboriginal and Torres Strait Islander people, including through Aboriginal and Torres Strait Islander primary health care services.

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## 8 Implementation

Implementation of the *National Hepatitis C Strategy* will take place at a number of levels and will involve many organisations and a wide range of mechanisms. Although implementation must be coordinated, it must also remain responsive to specific contexts at the local or community level and be sufficiently flexible to respond to future challenges.

State and Territory governments have a pivotal role in implementing this Strategy within their respective jurisdictions, in accordance with the identified priority areas. Their specific responsibilities are outlined in Chapter 7.

The Strategy will also be put into effect through the work plans of the Australian National Council on AIDS, Hepatitis C and Related Diseases and its committees. These work plans will be devised in collaboration with other members of the partnership and will last about 18 months. ANCAHRD will monitor the work plans and review them in its annual report to the Minister for Health and Aged Care.

There will also be an independent, external mid-term review of the Strategy's implementation.

At the State and Territory level, the Commonwealth–State–Territory Government Forum will coordinate efforts and develop nationally consistent reporting standards. Each State and Territory government should establish consultative forums, such as parliamentary liaison groups and ministerial advisory committees, that convene regularly so that all members of the partnership can participate in the Strategy's implementation.

To ensure effective delivery of hepatitis C services, local governments will be encouraged to become involved in the Strategy's implementation through developing and maintaining partnerships at their level. Where appropriate, activities at the local level will be monitored and reported on by the relevant State or Territory government.

Performance indicators contained in Commonwealth–State–Territory bilateral funding agreements will constitute an important mechanism for reviewing the Strategy's implementation at the State and Territory level.

ANCAHRD will advise the Minister for Health and Aged Care on the usefulness of these performance indicators and, if necessary, propose improvements for monitoring the Strategy's implementation.

Important links with other national population health strategies (as discussed in Chapter 2) will be maintained and developed through a range of internal and external mechanisms. Work plans under the Strategy must be sufficiently flexible to allow for the establishment of links with future national population health strategies as they develop.

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# 9 Monitoring and evaluation

Monitoring and evaluation mechanisms are needed to ensure that both policy and practice are based on the best available evidence and information and reflect the objectives and guiding principles of this *National Hepatitis C Strategy*. It is essential that there be transparent and systematic mechanisms for monitoring and evaluating the response to the epidemic, across all jurisdictions and by all partners.

## 9.1 Objectives

- To contribute to improved health outcomes by measuring the Strategy's performance with reference to its stated priority areas and objectives, at both the national and the State and Territory levels.
- To provide a mechanism for securing the accountability of all levels of government and other sectors.
- To provide a means of communicating to the wider community the successes of the Strategy and the challenges that await response.
- To ensure that the Strategy's priority areas and objectives are informed by the best available social and epidemiological evidence.
- To meet program managers' and policy makers' need for timely, accurate information about program performance, especially in the context of Commonwealth and State and Territory planning and program management.

## 9.2 Monitoring and evaluation mechanisms

Among the monitoring and evaluation mechanisms under this Strategy will be the following:

- ANCAHRD's annual report to the Commonwealth Minister for Health and Aged Care on the Strategy's implementation across each of the identified priority areas and against current work plans
- an independent, external mid-term review of the Strategy

- annual and other surveillance reports by the Communicable Diseases Network of Australia and New Zealand, under the *Australian Hepatitis C Surveillance Strategy*
- State and Territory governments' monitoring and evaluation of the Strategy's implementation in their respective jurisdictions, including performance indicators attached to Commonwealth–State–Territory funding agreements
- the publication on the Department of Health and Aged Care's website of State and Territory governments' performance information against agreed indicators in their respective Public Health Outcome Funding Agreements
- the monitoring activities of, among others, the national centres in HIV and hepatitis C research, the national centres for alcohol and other drug research, and the Department of Health and Aged Care
- commissioned evaluation of individual projects and initiatives, as determined by the Commonwealth and State and Territory governments
- 'feedback loops' and dissemination mechanisms from research projects
- assessment of the efficiency, effectiveness and appropriateness of the Strategy as part of the broader population health effort in Australia.

# Glossary

## **acquired immuno-deficiency syndrome**

a syndrome defined by the development of serious opportunistic infections, neoplasms or other life-threatening manifestations resulting from progressive HIV-induced immuno-suppression.

## **Australian National Council on AIDS, Hepatitis C and Related Diseases**

the Commonwealth Government's primary advisory body on HIV/AIDS and hepatitis C, established to provide independent and expert advice to the Minister for Health on the implementation of the National Hepatitis C Strategy. It is principally concerned with the identification of national needs, objectives and priorities and takes a public information role in matters related to HIV/AIDS and hepatitis C.

## **basic scientific research**

develops knowledge, techniques and expertise that can be applied to research into specific disease processes and the development of population health policies and interventions.

## **best practice**

on the evidence available, the best intervention to produce improved outcomes for an identified problem.

## **blood borne virus**

a virus that is transmitted via blood or body fluids that contain blood. Such transmission can result from sharing injecting equipment.

## **clinical research**

health research relating to individual patients as well as the development and evaluation of treatments for diseases.

## **clinical trial**

a research activity designed to test a drug or treatment and so establish its efficacy and safety and to identify groups of patients who can be expected to benefit from such a drug or treatment.

**co-infection**

in this context, the term used to describe the circumstance in which a person is concurrently infected with hepatitis C and another blood borne virus such as HIV.

**combination therapy**

the use of two or more types of treatment in combination, alternately or together, to achieve optimum results and reduce toxicity.

**Commonwealth–State–Territory Government Forum**

a forum for regular Commonwealth and State and Territory government liaison and coordination on policy, finance, programs and activities related to HIV/AIDS and hepatitis C. Membership consists of an independent chairperson nominated by the Australian Health Ministers Advisory Council, representatives of each of the Commonwealth, State and Territory departments responsible for health, a representative of each of the departments responsible for health in Papua New Guinea and New Zealand, and representatives of the communities affected by HIV and hepatitis C. The Forum is known as the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases and is a standing committee of the National Public Health Partnership Group.

**communicable disease**

a disease caused by a specific infectious agent or its toxic products that arises through transmission of that agent or its products from an infected person, animal or other reservoir to a susceptible host.

**complementary therapies**

therapies that are provided by a naturopath, a herbalist or someone practising Chinese medicine. In the context of hepatitis C, the treatments provided may be used against the virus itself or to lessen the side effects of chronic hepatitis C infection or other hepatitis C treatment regimes.

**continuum of care**

an integrated, client-oriented system of care consisting of services and integrating mechanisms that support clients over time, across a comprehensive array of health and social services, and spanning all levels of intensity of care.

**culturally appropriate**

a term used to describe activities and programs that take into account the practices and beliefs of a particular social group, so that the programs and activities are acceptable, accessible, persuasive and meaningful.



**custodial settings**

in this context, the various settings in which adults and juveniles can be detained or imprisoned, including prisons, juvenile justice centres, and remand and other detention facilities.

**demand reduction interventions**

interventions designed to reduce the desire for and preparedness to obtain and use illicit drugs. Such interventions seek to prevent the uptake of harmful drug use and include abstinence-oriented interventions aimed at reducing illicit drug use and drug related harm.

**discrimination, hepatitis C related**

any unfavourable treatment on the basis of known or imputed hepatitis C status; any action or inaction that results in a person being denied full or partial access to otherwise generally available services or opportunities because of known or imputed hepatitis C status. The definition includes discrimination on the grounds of known or imputed membership of particular groups that are commonly associated with hepatitis C.

**drug related harm**

any adverse social, physical, psychological, legal or other consequence of drug use that is experienced by a person using drugs or by people living with or otherwise affected by the actions of a person using drugs.

**epidemiology**

the study of the distribution and determinants of health related states or events (such as likely routes of transmission of disease and trends in epidemics) in specified populations and the application of this knowledge to deal with health problems.

**evidenced-based practice**

involves integrating the best available evidence with professional expertise to make decisions.

**genotype**

a term used to classify the RNA genome of the hepatitis C virus according to the nucleotide sequence of defined regions of the genome.

**harm minimisation**

the primary principle underpinning the National Drug Strategic Framework. The term refers to policies and programs aimed at reducing drug related harm. Underlying the principle is the intention to improve health, social and economic outcomes for both the community and the individual. Various approaches are involved, including abstinence-oriented strategies. Both licit and illicit drugs are

the focus of Australia's harm-minimisation strategy. Harm minimisation includes preventing anticipated harm and reducing actual harm. It is consistent with a comprehensive approach to drug related harm, involving a balance between demand reduction, supply reduction and harm reduction.

### **harm reduction interventions**

interventions designed to reduce the impacts of drug related harm on individuals and communities. Governments do not condone illegal risk behaviours such as injecting drug use; they acknowledge that these behaviours occur and that they have a responsibility to develop and implement population health measures designed to reduce the harm that such behaviours can cause.

### **health maintenance**

in this context, promoting approaches, interventions and lifestyle choices that support continued management and monitoring of a person's health with the intention of reducing the severity and side effects of chronic hepatitis C infection and deferring the onset of advanced liver disease.

### **hepatitis C virus**

an RNA virus transmitted through blood-to-blood contact.

### **Highly Specialised Drugs Program**

provides access (as Pharmaceutical Benefits Schedule items) to certain medicines for chronic conditions that because of their clinical use or other characteristics are restricted to supply through hospitals having access to appropriate specialist facilities.

### **human immuno-deficiency virus**

a human retrovirus that leads to AIDS.

### **illicit drug**

a drug whose production, sale or possession is prohibited.

### **incidence**

the number of new cases of a disease in a defined population within a defined period.

### **National Public Health Partnership**

a broad, multilateral intergovernmental framework that enables a cooperative approach to the improvement of the population health system and clarifies the roles and responsibilities of its principal partners. Membership consists of senior health officials from the Commonwealth and each State and Territory, the Australian Institute of Health and Welfare and the National Health and Medical Research Council.

**needle and syringe programs**

programs authorised to distribute, dispose of or sell needles and syringes.

**Parliamentary Liaison Group**

a non-partisan forum through which information is provided to members of the Commonwealth Parliament and in which policy discussion occurs.

**PCR**

polymerase chain reaction—a test to detect genetic material (DNA or RNA) in serum or tissues. Used to detect hepatitis C RNA.

**peer education**

any education process devised and implemented by members of a population subgroup specifically to alter the behaviours and attitudes of other members of that subgroup; for example, gay men delivering education programs relating to gay men's sexual health.

**people affected by hepatitis C**

people at risk of acquiring an infection, people with existing infection, and others such as carers and partners who, while not directly infected with the virus, are nonetheless affected by the hepatitis C epidemic.

**prevalence rate**

the number of individuals who have an attribute or disease at a particular time or period divided by the population risks of having the attribute or disease at that time or midway through the period.

**prophylaxis**

any measure taken to prevent an adverse outcome from occurring, such as prescribing medication that is known to prevent an infection from taking hold at a time when a person may not be infected or ill but is at risk of developing that infection or illness. In the context of hepatitis C, agents that might be used as post-exposure prophylaxis are still in early development stages.

**seroconversion**

the development of a detectable level of antibodies that occurs after a person has been exposed to and become infected by a micro-organism such as the hepatitis C virus.

**sexually transmissible infection**

an infection—such as HIV, gonorrhoea, syphilis or chlamydia—that is transmitted through sexual contact.

**shared care**

arrangements for providing a continuum of health care where care and advice are shared between primary care physicians and specialists such as gastroenterologists, hepatologists or infectious diseases specialists.

**social and behavioural research**

research designed to identify the social and behavioural factors that affect disease transmission with the aim of enabling the development of specific interventions for specific groups. Social research also identifies support networks and quality-of-life factors to be considered in population health policies.

**supply reduction interventions**

interventions designed to disrupt the production and supply of illicit drugs.

**surveillance**

in this context, the continuing scrutiny of all aspects of the occurrence and spread of a disease. The main purpose is to detect changes in trends or distribution in order to initiate investigative or control measures.

**user group**

community-based organisations representing the interests of people who use drugs illicitly.

**viral load**

the amount of virus present per cubic millilitre of blood, as measured by a viral-load test.

**virology**

the science of investigating virus structure, mode of action and disease processes and the identification of possible interventions at the cellular level. Developments in virological research can also contribute to the development of drug or vaccine therapies.

# Abbreviations

AHMAC	Australian Health Ministers Advisory Council
AIDS	acquired immuno-deficiency syndrome
ANCARD	Australian National Council on AIDS and Related Diseases
ANCAHRD	Australian National Council on AIDS, Hepatitis C and Related Diseases
DNA	deoxyribonucleic acid
HIV	human immuno-deficiency virus
NHMRC	National Health and Medical Research Council
PCR	polymerase chain reaction
RNA	ribonucleic acid

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