

**National  
Hepatitis C  
Strategy**

**2005-2008**

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# Foreword

Hepatitis C is a significant public health issue for Australia, believed to affect about 1 per cent of the community. Hepatitis C is now the most common reason for Australians to need liver transplants.

With an estimated 16,000 new infections each year, it is not inappropriate to talk about an epidemic of hepatitis C. We must remain vigilant in our efforts to reduce the impact of this disease on Australians.

Hepatitis C is a slow-progressing, blood borne viral disease. Often, people are unaware they are infected until symptoms present many years later.

Many people in the community are not aware of the risk factors for contracting hepatitis C and unknowingly engage in behaviours that put them at risk.

Injecting drug use is the leading risk behaviour for transmission of hepatitis C. In particular, the sharing of injecting equipment poses the greatest risk of exposure to the hepatitis C virus. Approximately 80 per cent of current infections and 90 per cent of new infections are estimated to be due to unsafe injecting drug use practices.

The 2004 National Drug Strategy Household Survey showed that there are over 70,000 injecting drug users in Australia. The Government is committed to its "Tough on Drugs" strategy which was launched by the Prime Minister in November 1997. Since its launch, the Australian Government has allocated more than \$1 billion to the Strategy for a range of supply, demand and harm reduction measures. This commitment represents the largest single initiative ever undertaken in this country to reduce the supply of, and demand for, illicit drugs. It brings together law enforcement, health, education and family portfolios and the non government sector in the pursuit of a government agenda around a reduction in the use of, and ultimately abstinence from, illicit drugs.

The Government is committed to efforts to improve community awareness of hepatitis C, and also to assist people who do contract hepatitis C to access early testing, diagnosis and treatment.

This National Hepatitis C Strategy 2005-2008 has been developed by my department in partnership with people affected by hepatitis C, governments at all levels, and medical, scientific and health care professionals. The Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis, and its Hepatitis C Subcommittee have been instrumental in the development of the new Strategy and will steer Australia's response to hepatitis C. The successful development of the new Strategy highlights the Australian Government's commitment to work with all stakeholders to reduce transmission rates and the physical and social impact of the disease on people living with and affected by hepatitis C.

Continuing actions to combat this disease will be guided by this second National Hepatitis C Strategy.

The new National Hepatitis C Strategy 2005-2008 identifies seven priority areas, of which three will become the central focal points for action because they have the most potential for reducing transmission of the disease.

These are:

- improving access to treatment and support, and increasing treatment uptake among people with hepatitis C,
- improving and increasing the reach of prevention and education efforts, and
- improving the current hepatitis C surveillance system.

There should be improvements in each of these areas over the next three years.

I am confident this new Strategy will enhance the cooperative national approach to hepatitis C established through the first Strategy and provide a strong, yet flexible framework for responding to any future challenges the epidemic may present.

I hope each member of the partnership will continue their commitment to the objectives of this new Strategy and use their unique perspectives and abilities to address the priority action areas.

TONY ABBOTT

Minister for Health and Ageing

# Executive Summary

Hepatitis C continues to be one of the most commonly reported notifiable infectious diseases in Australia. With 242,000 people thought to be living with the virus, and an estimated 16,000 new infections occurring annually, the urgent need to address this epidemic cannot be overstated.

In 1999, Australia became a world leader in its strategic response to hepatitis C by developing the National Hepatitis C Strategy 1999–2000 to 2003–2004, the first strategic document of its kind. The first National Hepatitis C Strategy is generally recognised to have established a sound approach to combating the high levels of hepatitis C in Australia, including a firm partnership between all levels of government, community based organisations, health professionals, researchers and people with or at risk of hepatitis C.

The National Hepatitis C Strategy 2005–2008 builds on the successes of the first Strategy. With so many people living with hepatitis C, and such high transmission rates, it is particularly important to strengthen prevention efforts for those most at risk and to improve their access to testing, treatment and support services.

This National Hepatitis C Strategy recognises people who inject drugs, people in custodial settings and Aboriginal and Torres Strait Islander people who engage in risk behaviours as those disproportionately affected by hepatitis C. To achieve the aims of this National Hepatitis C Strategy, education, prevention, treatment and care and support services must be strongly targeted towards these groups.

Seven priority areas for action are identified in this National Hepatitis C Strategy, where efforts must be maintained and enhanced if the Australian response to hepatitis C is to be effective. These are prevention and education, treatment and diagnosis, surveillance, research, health maintenance, care and support, workforce development and addressing discrimination and stigma. While it is important that work proceed in all these areas, this National Hepatitis C Strategy will focus on three specific actions that have the most potential to reduce hepatitis C transmission, reduce the associated burden of disease and increase our understanding of the virus and its risk factors.

The first of these is to improve access to treatment and increase treatment uptake among people with hepatitis C. Advances in the efficacy of hepatitis C treatment indicate it is now possible for at least 50 per cent of people who undergo treatment to become cured, with success rates even higher for those with particular genotypes. Despite this, only about 1 per cent of those diagnosed with hepatitis C are being treated annually. More needs to be done to increase treatment numbers, as this has the potential to significantly improve quality of life for people with hepatitis C and reduce the burden of disease and health care costs associated with the virus in Australia. Treatment can also be a form of secondary prevention, as people who have successfully undergone treatment no longer pose a transmission risk to others.

Primary prevention is still of paramount concern. Needle and Syringe Programs (NSPs) have been enormously successful in preventing blood borne virus infections in Australia over the last 15 years, but continuing high hepatitis C transmission rates make it imperative to strengthen and diversify prevention efforts. This must include improving the capacity of programs such as NSPs, drug education and treatment programs to offer education about

hepatitis C, and ensuring groups with previously poor access to the information and means of preventing hepatitis C infection (such as Aboriginal and Torres Strait Islander people who engage in risk behaviours, people in custodial settings and people from culturally and linguistically diverse backgrounds) are made aware of what hepatitis C is and how they can avoid it.

Finally, knowledge of the characteristics of the hepatitis C epidemic in Australia remains incomplete. Improvements to the current surveillance system are needed to give a true picture of the extent of the epidemic, and of the behaviours and contexts which place people at risk of hepatitis C.

Though hepatitis C is a serious problem which warrants a specific response, it is important to realise this is not a stand alone Strategy. Rather, it sits within a communicable diseases framework alongside other complementary strategies, most notably the *National HIV/AIDS Strategy 2005–2008*, the *National Sexually Transmissible Infections (STIs) Strategy 2005–2008* and the *National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy 2005–2008*. These four strategies have the common goal of reducing the transmission of infectious diseases and improving treatment, care and support for those affected. They are all based on similar guiding principles, which include commitment to the 1986 Ottawa Charter for Health Promotion, to a partnership approach between governments, community based organisations, health care providers, researchers and affected communities, to equality in access to services and finally to the centrality of people with or at risk of STIs and blood borne viruses in the national response.

Groups such as people who inject drugs, young people, people in custodial settings and Aboriginal and Torres Strait Islander people may be at risk of HIV, STIs and hepatitis C. Interventions aimed at these groups must account for this multiple risk and offer prevention, testing, treatment and support services which recognise and address the possibility of co-infection. One way of doing this is through workforce education and training for health care providers who come into contact with people at risk of both blood borne viruses and STIs. These include general practitioners, alcohol and other drug services, sexual health clinics, Aboriginal and Torres Strait Islander primary health care services and youth services.

Similarities will be further explored in implementation of the four strategies. The Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH) and its three subcommittees—the HIV/ AIDS and STIs Subcommittee, Hepatitis C Subcommittee and Indigenous Australians' Sexual Health Committee—will oversee this implementation process and report annually to the Minister for Health and Ageing on progress of all four strategies. In doing so, the MACASHH and its subcommittees will provide advice on how to strengthen linkages between these strategies and with other related documents, such as the National Drug Strategy 2004–2009 and the National Aboriginal and Torres Strait Islander Health Strategic Framework. The MACASHH will also collaborate with advisory committees working on similar issues, such as the Australian National Council on Drugs.

Other partners, such as State and Territory Governments, researchers and community based organisations, are equally vital in successful implementation of the strategies. Each of the four strategies aims to provide all partners with the flexibility to tailor programs towards their jurisdictions and constituencies. The similarities between the HIV/AIDS, STIs and hepatitis C epidemics must be borne in mind when designing State and local level interventions.



Criticisms of the monitoring and evaluation of the first National Hepatitis C Strategy were a key focus of the first strategy's review in 2002. Effective monitoring and evaluation will occur during the life of this National Hepatitis C Strategy to ensure that policy and practice are based on the best and most up to date evidence. An implementation plan and evaluation framework developed and endorsed by the partnership will facilitate implementation and the monitoring and evaluation process. Also, an annual strategic issues workshop involving all stakeholders will serve to strengthen partnerships and ensure that emerging priorities are addressed.

Reporting against the implementation and evaluations plans will form the basis of an annual report which, with input from the partnership, will be submitted to the Minister for Health and Ageing, through the MACASHH and IGCAHRD.

These processes in place will ensure that Australia's response to hepatitis C maintains its momentum, while being flexible enough to accommodate emerging priorities.

# 1 Goal and objectives

## 1.1 Goal

*To reduce transmission and minimise the personal and social impacts of hepatitis C.*

The *National Hepatitis C Strategy 2005–2008* (this National Hepatitis C Strategy) provides a framework for a coordinated integrated response to hepatitis C in Australia. It identifies priorities for action over the next three years, and builds upon the experience and achievements of the first *National Hepatitis C Strategy 1999–2000 to 2003–2004*.

Over the life of the first strategy, these achievements have included establishment of a strong partnership approach, and advances in the treatment of chronic hepatitis C which indicate it is now possible to cure infection completely in around half of those with hepatitis C who require treatment.

Implementation of this National Hepatitis C Strategy will be guided by key advisory and decision making bodies and will be a shared responsibility of all levels of government, health care professionals, researchers and community based organisations.

This National Hepatitis C Strategy recognises that, regardless of how hepatitis C is acquired, the social, medical and economic impacts for individuals and for the broader community can be profound. It acknowledges that the most effective way to reduce the harm resulting from hepatitis C infection is to minimise exposure to the virus. It also recognises the need for improved access to testing, treatment, care and support for those affected.

The people who will use and be informed by this National Hepatitis C Strategy include policy makers, the Australian community (including people with or at risk of hepatitis C) researchers, health care professionals and other service providers.

## 1.2 Objectives

The following objectives of the National Hepatitis C Strategy will contribute to a reduction in transmission of hepatitis C and reduce its impact on the lives of individuals and communities:

1. Reduce transmission of the hepatitis C virus through education, improved awareness of risks and access to harm reduction strategies.
2. Maximise the health and wellbeing of people with hepatitis C by providing equitable access to appropriate testing, treatments, information and support services.
3. Reduce the discrimination, isolation and stigma experienced by people with hepatitis C, through raising community awareness of hepatitis C and its consequences.
4. Promote evidence based prevention, treatment and support services through strategic and basic virological, clinical and social research.
5. Undertake surveillance and monitoring to identify groups at risk, guide prevention interventions and evaluate effectiveness of these interventions.
6. Develop and strengthen links with other related national strategies.

### 1.3 Guiding principles

The 1986 Ottawa Charter for Health Promotion<sup>1</sup> underpins this National Hepatitis C Strategy. The Charter defines health promotion as 'the process of enabling people to increase control over, and to improve their health'. The National Hepatitis C Strategy will assist in this process by:

- building healthy public policy through establishing strong links between the health sector and areas such as justice and education around hepatitis C related issues;
- creating supportive environments by attempting to reduce the stigma and social isolation experienced by people with hepatitis C;
- strengthening community action by supporting health services and community based organisations (including peer based organisations) to develop and implement programs tailored to the diverse groups of people with or at risk of hepatitis C;
- developing personal skills by providing people with or at risk of hepatitis C with the information and means to reduce transmission, as well as improve and maintain their own health; and
- reorientating health services to provide holistic, non judgemental care and support to people with or at risk of hepatitis C.

With these general aims in mind, the National Hepatitis C Strategy will also be guided by the following specific principles:

- a partnership between all levels of government, community based organisations, health care professionals, researchers and people affected by hepatitis C, which is fundamental to the effectiveness of this Strategy;
- a social determinants model of ill health, which recognises that factors such as poverty, housing, employment and legal issues influence a person's ability to manage their own health;
- equitable access for all people with or at risk of hepatitis C to the means of prevention, information, education, testing, treatment, care and support;
- harm reduction, which does not condone drug use but refers to policies and programs aimed at reducing drug related harm. Harm reduction interventions aim to improve health, social and economic outcomes for the community and the individual, and encompass a wide range of approaches, including NSPs, abstinence orientated strategies and assisting people with drug dependencies to seek treatment;
- the involvement of people with or at risk of hepatitis C in the development, implementation and evaluation of all activities, which is critical to an effective response; and
- implementation of this National Hepatitis C Strategy to be underpinned by the best available evidence.

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<sup>1</sup> This Charter was adopted at the First International Conference on Health Promotion, held in Ottawa on 21 November 1986.

# 2 Hepatitis C in Australia

## 2.1 What is hepatitis C?

Hepatitis C is a blood borne virus, and is transmitted from one person to another by blood to blood contact. Transmission can occur through:

- sharing equipment used to inject drugs: 80 per cent of current infections and 90 per cent of new infections <sup>ii</sup> are estimated to be due to unsafe injecting practices;
- non-sterile tattooing or body-piercing: although all jurisdictions regulate invasive Body Art procedures to minimise the risk of blood borne infections, tattooing and body piercing outside of regulated environments may still involve unsterile practices;
- mother-to-child transmission during delivery: there is a less than 5 per cent risk of vertical transmission <sup>iii</sup> if the mother has chronic hepatitis C and detectable viremia <sup>iv</sup>;
- unsterile medical or dental procedures: people may have acquired hepatitis C through unsterile medical procedures in their country of birth. Anecdotal evidence suggests that approximately 10–15 per cent of people with hepatitis C in Australia are from culturally and linguistically diverse backgrounds;
- infected blood or blood products: approximately 5 to 10 per cent of people with hepatitis C acquired the virus through transfusion of blood and blood products in the 1970s and 1980s<sup>v</sup>.

Since 1990 all blood and blood products in Australia have been screened for hepatitis C antibodies. The risk of transmission through blood transfusions is now extremely low; Many people with haemophilia will have received large quantities of blood products in the course of treatment for their condition and there is a high incidence of hepatitis C in this group. Also, nearly all people with haemophilia in Australia who have HIV are co-infected with hepatitis C <sup>vi</sup>; and

- needlestick injuries and accidental exposure to infected blood or blood products in health care settings.

Sexual transmission of hepatitis C is possible, but uncommon. Such transmission only occurs where the blood of a person with hepatitis C enters the blood stream of another person.

Hepatitis C is not transmitted through casual contact such as hugging, sneezing, coughing, sharing food and drinks, or through mosquito bites. Any low risk of domestic or household transmission of hepatitis C can be avoided if items such as razors and toothbrushes are not shared.

Around 75 per cent of people exposed to hepatitis C virus infection will progress to chronic hepatitis C, as defined by presence of the hepatitis C virus in a person's bloodstream beyond 6 months. The other 25 per cent of people will clear the infection within 6 months but will continue to have detectable hepatitis C antibodies, often for decades. Exposure to the virus with subsequent clearance does not lead to immunity and hepatitis C reinfection can occur following re-exposure.

A key achievement in recent years has been in the treatment of hepatitis C. Recent evidence indicates between 80 to 90 per cent of people with genotype 2 or 3 of the virus, and up to 50 per cent of people with genotype 1 or 4 who undergo treatment will be cured with available therapies<sup>3</sup>. People who successfully complete treatment no longer experience hepatitis C related symptoms or progression to severe liver disease<sup>vii, viii, ix, x</sup>. Although treatment is not appropriate for everyone with hepatitis C, improving access and encouraging people living with hepatitis C to undergo treatment has the potential to reduce transmission and to reduce the burden of disease associated with hepatitis C in Australia.

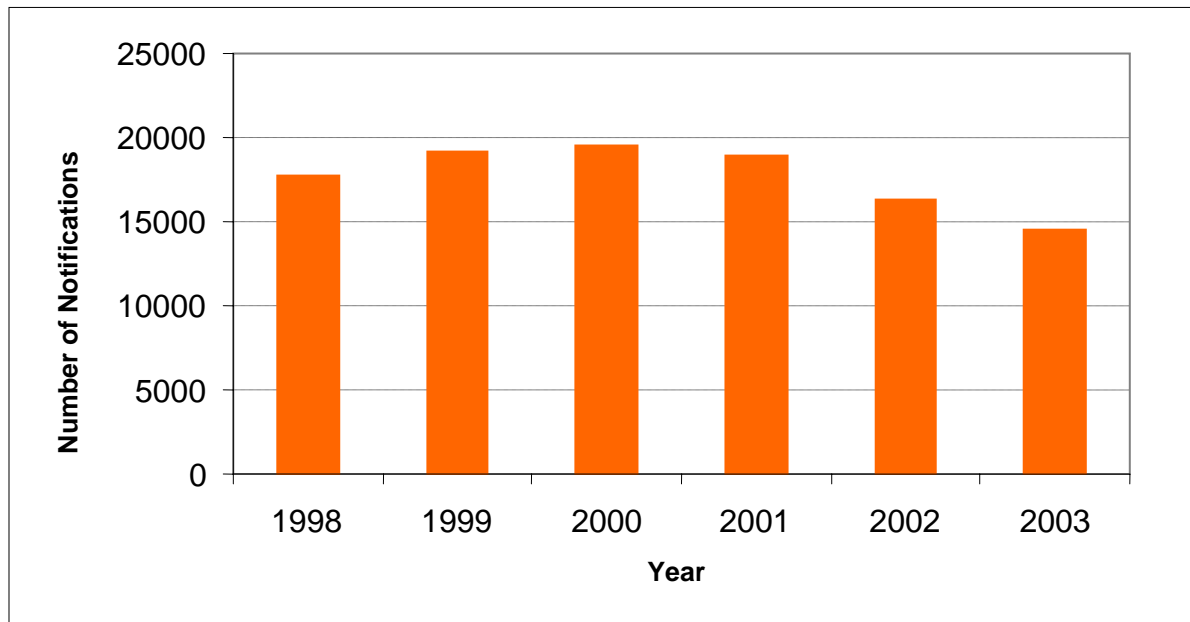
At present there is no vaccine to protect against hepatitis C, though research in this area is continuing.

## 2.2 How many people have hepatitis C in Australia?

There was an estimated 242,000 people with hepatitis C in Australia by the end of 2003<sup>xi</sup>, with 16,000 new infections projected to be occurring annually. By 2020, projections of the number of people living with hepatitis C are likely to be between 321,000 and 836,000, depending on future patterns of injecting drug use<sup>xii</sup>.

Recent evidence suggests the number of new hepatitis C infections may have declined from 2001. Levels and patterns of hepatitis C testing appear unchanged; therefore the decline in diagnoses may be attributed to a decline in incidence.

**Figure 1: Trends in the notifications of hepatitis C in Australia between 1998 and 2003**



Source: NCHECR Annual Surveillance Report 2004, Table 2.1.7

<sup>3</sup> Cure is generally accepted as no detectable virus in the blood 6 months after treatment completion. Studies confirm that the majority of those with no detectable virus at 6 months continue to be virus free at 4 years. Studies are ongoing.

Approximately 80 per cent of people with hepatitis C in Australia are estimated to have been diagnosed. The diagnosis rate in Australia appears to be much higher than comparable countries such as the US and UK <sup>ii</sup>, though there are still potentially a number of people with hepatitis C in Australia who remain undiagnosed. As hepatitis C is a slowly progressing disease, people may live with the virus for many years without experiencing symptoms. The total number of people living with hepatitis C will continue to increase while treatment levels and general awareness of the behaviours which place people at risk remain low <sup>v</sup>.

The estimates of hepatitis C prevalence and incidence in Australia need to be considered within the context of limitations in current surveillance systems. Estimates of population prevalence of hepatitis C are largely dependent on estimates of the number of people who inject drugs and the incidence of hepatitis C in this group. Limited population-based data is available on hepatitis C prevalence, and current testing technology does not differentiate between recent and chronic infection. Uncertainty around hepatitis C prevalence rates is particularly acute for groups such as Aboriginal and Torres Strait Islander people.

### **2.3 Priority populations at risk of hepatitis C infection**

People with or at risk of hepatitis C come from all sectors of the Australian community and their experience of hepatitis C varies dramatically according to individual and community circumstances. The priority action areas must recognise this diversity if this National Hepatitis C Strategy is to be effective.

This National Hepatitis C Strategy will strive to ensure all people with or at risk of hepatitis C have equitable access to appropriate prevention, testing, treatment, care and support services. However, there are three groups overwhelmingly at risk of hepatitis C. This National Hepatitis C Strategy will pay particular attention to reducing transmission and improving care and support for these groups.

#### **People who inject drugs**

People who inject drugs are at greatest risk of contracting hepatitis C. Approximately 80 per cent of current infections and 90 per cent of new infections are estimated to be due to unsafe injecting drug use practices <sup>ii</sup>. In 1997 it was estimated that 100,000 Australians regularly inject drugs, with an additional 175,000 involved in occasional injecting without dependence or social disruption <sup>ii</sup>.

Hepatitis C continued to be reported at high levels in 2003 among attendees at NSPs, with prevalence rates of 57 per cent for males and 61 per cent for females <sup>xiii</sup>. Hepatitis C prevalence among male and female attendees aged less than 20 years increased from 28 per cent in 1999 to 39 per cent in 2001 before declining slightly to 32 per cent in 2003.

There is considerable evidence that people who inject drugs face discrimination on the basis of their drug use, particularly in health care settings <sup>xiv</sup>. As a result, many people who inject drugs have quite poor levels of general health which may be compounded by other social problems such as poverty, unemployment and poor access to housing, welfare and other support services. In this context, hepatitis C may be only one issue in a long line of health and other priorities for people who inject drugs. There is an urgent need to increase access to primary health care services for this group, to allow them to address their most pressing and immediate health concerns, thereby increasing their capacity to focus on other health needs such as hepatitis C.

People who inject drugs are also a diverse group. Sub-populations with particular needs include:

*Young people:* Research indicates the median age of initiation into injecting drug use is 18 years. Young people need access to education and skills so they are knowledgeable about hepatitis C, the behaviours which place them at risk of hepatitis C, and the ways in which they can avoid such risk.

*People from culturally and linguistically diverse (CALD) backgrounds:* Unsafe injecting practices among CALD injecting drug users account for some hepatitis C transmission, with several studies finding very high levels of hepatitis C among CALD injecting drug users, particularly those from South East Asian backgrounds <sup>xv</sup>. CALD injecting drug users require prevention, treatment and health maintenance services that are culturally appropriate and in a language they understand.

*People in rural and remote areas:* Access to education, skills and the necessary equipment for maintaining preventive practices (for example through NSPs) are often extremely limited in rural, regional and remote areas. Community sentiment, a lack of confidentiality and judgemental attitudes by some health care workers can also severely hinder the prevention and treatment of hepatitis C infection.

### **People in custodial settings**

There are no nationally standardised data on hepatitis C in custodial settings. It has been estimated, however, that hepatitis C prevalence is in the range of 30 to 40 per cent for all prisoners, and between 50 to 70 per cent for female prisoners <sup>xvi</sup>. This indicates that hepatitis C prevalence in custodial settings is much greater than the prevalence of approximately 1 per cent found in the general community.

The high proportion of people entering prison for drug related offences, coupled with unsafe injecting drug use within custodial settings, places this group at high risk of hepatitis C transmission. To date there has been one comprehensive study of injecting drug use in custodial settings in Australia-the 2001 Inmate Health Survey conducted in New South Wales. This survey found 53 per cent of male inmates and 73 per cent of female inmates reported a history of injecting drug use. A significant proportion (24 per cent of male inmates and 43 per cent of female inmates) continued to inject while in custody <sup>xvii</sup>. Other high risk behaviours common in custodial settings include body piercing, tattooing, injury, self harm, fighting and assaults.

Inmates do not have access equivalent to the general community to the means of preventing hepatitis C transmission. NSPs have not been implemented in any Australian prison and a high proportion of inmates report reuse of a needle or syringe after someone else <sup>xvi</sup>. Tattooing and body piercing also pose a particular problem in custodial settings where these procedures are often performed by untrained operators without access to sterile equipment.

Other harm reduction measures such as peer based drug education, hepatitis B vaccination and bleach provision are available in some jurisdictions. The availability of testing for hepatitis C also varies, with testing compulsory upon admission in the Northern Territory, voluntary in Victoria and Western Australia, and available upon inmate request or clinical indications in other jurisdictions <sup>xvi</sup>.

Structural barriers to the provision of health care in custodial settings make it difficult for many inmates to utilise hepatitis C treatment and related specialist services. Inmates currently do not have access to treatment subsidised through the Pharmaceutical Benefits Scheme, therefore the

considerable costs of hepatitis C treatment must be borne by State and Territory Governments. Treatment availability is therefore restricted by limited correctional health budgets.

Given high rates of turnover among inmates and lack of post release follow up, the significant risk of hepatitis C transmission in custodial settings has the potential to translate into increased infection rates in the general community once inmates are released.

### **Aboriginal and Torres Strait Islander people who engage in risk behaviours**

Reporting of Aboriginal and/or Torres Strait Islander status on hepatitis C notifications is less than 50 per cent in some jurisdictions<sup>xi</sup>. The most recent surveillance data show that for those jurisdictions where Aboriginal and/or Torres Strait Islander status is better recorded there are higher rates of hepatitis C reported in the Aboriginal and Torres Strait Islander population<sup>xv</sup>.

Aboriginal and Torres Strait Islander people may be at increased risk of hepatitis C transmission for the following reasons:

*Injecting Drug Use:* Aboriginal and Torres Strait Islander people have a population which is younger, more mobile and much more marginalised than the population at large. Consequently, they may be more likely to participate in risk taking behaviour. For example, homelessness leads some Aboriginal and Torres Strait Islander injecting drug users to inject in outdoor settings, where they are less likely to have access to cleaning agents and therefore more likely to share unsterile injecting equipment<sup>xviii</sup>.

Furthermore, Aboriginal and Torres Strait Islander injecting drug users may experience disapproval and social marginalisation within their own communities, and are unwilling to seek out the means of prevention, for example through NSPs<sup>xviii</sup>.

The national NSP survey found the proportion of people who inject drugs identifying as Aboriginal and/or Torres Strait Islander increased from 5 per cent in 1995 to 8 per cent in 2003<sup>xiii</sup>. This compares to an Aboriginal and Torres Strait Islander population of 2.2 per cent in Australia. The survey also found hepatitis C prevalence among people who inject drugs was similar for Indigenous (63 per cent) and non-Indigenous (58 per cent) users. This figure could be higher, as Aboriginal and Torres Strait Islander people who inject drugs may be less likely to access NSPs or participate in surveys.

*Incarceration:* Aboriginal and Torres Strait Islander people are significantly overrepresented in adult and juvenile correctional settings. As at June 2002, 20 per cent of all prisoners identified as Aboriginal and Torres Strait Islander. On a per capita basis, Indigenous Australians have an incarceration rate which is ten times higher than the non-Indigenous Australians<sup>xix</sup>. There is some evidence that custodial settings provide an important point for initiation into injecting drug use for Aboriginal and Torres Strait Islander prisoners. The high rates of injecting drug use in custodial settings, coupled with higher incarceration rates place Aboriginal and Torres Strait Islander people at increased risk of hepatitis C transmission.

*Poor Access to Services:* The lower levels of access to health and related services by Aboriginal and Torres Strait Islander people are well documented. This relates both to primary health care and specialist services and to specific blood borne virus services such as NSPs and peer education. The limited availability of culturally appropriate services places Aboriginal and Torres Strait Islander people at further risk of not accessing medical care. For this reason, Aboriginal and Torres Strait Islander primary health care services have an integral role to play in addressing hepatitis C related issues among Aboriginal and Torres Strait Islander people.



## 2.4 How does hepatitis C affect health?

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, then decline following development of the hepatitis C specific immune response. People with a stronger and well-targeted immune response are more likely to clear infection. There are no readily identifiable factors which can predict who will clear infection and who will progress to chronic hepatitis C.

People with chronic hepatitis C are at risk of progressive liver disease. Without effective therapeutic intervention, an estimated 20 per cent will develop cirrhosis over a 20–40 year period. The risk of progressive liver disease is higher among people with heavy alcohol intake, co-infection with chronic hepatitis B or HIV, fatty liver disease (associated with obesity) and those who have acquired hepatitis C at an older age (above 40 years). Advanced liver disease complications from hepatitis C related cirrhosis include liver cancer (hepatocellular carcinoma) and liver failure. Hepatitis C related advanced liver disease has become the major underlying reason for liver transplantation in Australia.

Irrespective of trends in incidence, hepatitis C will continue to have serious implications for the burden of disease in Australia. Projections indicate that without a substantial increase in treatment figures, the number of people with hepatitis C related cirrhosis will treble to between 21,000 and 26,000 by 2020. Rates of hepatocellular carcinoma and hepatitis C related liver failure are expected to show similar patterns of growth <sup>xx</sup>.

People with chronic hepatitis C, including those with early or non-progressive liver disease, may have considerable hepatitis C related symptoms and impaired quality of life. In 2001 it was estimated that 22,500 quality years of life were lost due to hepatitis C infection in Australia <sup>ii</sup>. Common hepatitis C related symptoms include tiredness, lethargy, nausea, headaches, depression, aches and pains in joints and muscles, poor dental health and discomfort in the upper abdomen area.

A variety of other physical conditions can affect the health and wellbeing of people with hepatitis C. For example, people can be infected with two or more blood borne viruses. Co-infection with HIV or hepatitis B exacerbates the symptoms of hepatitis C and causes a faster progression to severe liver disease. Like other chronic conditions, hepatitis C places additional stress on a person's emotional wellbeing. Conditions such as depression and anxiety can either be pre existing or induced by hepatitis C diagnosis. These conditions also exacerbate the ill health experienced by people with hepatitis C and further complicate the types of care and support services they need.

## 2.5 The personal, social and economic impact of hepatitis C

The personal consequences of hepatitis C on individuals can be severe. As well as the obvious impact on health and wellbeing, effective management of infection may require individuals to make changes to their lifestyle, such as reducing hours of work and modifying behaviours to lower the risk of passing the virus on to others.

The social implications of hepatitis C result from disclosure of infection within a community largely uneducated about hepatitis C transmission, and the stigmatisation, and marginalisation of people who inject drugs. Disclosure of hepatitis C status can result in alienation from family and friends as well as discrimination in health services and workplaces <sup>v</sup>.

People with hepatitis C are members of the broader community. Their friends and families are also affected by the presence of the virus, and require information and support to care for people with hepatitis C.

Conservative estimates of direct and indirect costs of hepatitis C to the community in 1996–97 amount to \$107.5 million for people with existing infections, with estimated lifetime<sup>4</sup> costs rising by \$46.6 million for every 1000 new infections<sup>xxi</sup>. With high numbers of existing and new infections, hepatitis C will continue to have serious implications for Australia’s health care system for many years.

## 2.6 Australia’s response

To date, the Australian Government’s commitment to a nationally coordinated response to hepatitis C has been expressed in a number of strategic documents.

In 1994, the *National Hepatitis C Action Plan* was released, followed by a *Nationally Coordinated Hepatitis C Education and Prevention Approach* in 1995. These documents detailed the priority areas for action in the national approach and outlined a program of education activities.

In 1996, hepatitis C was included under the aegis of the *National HIV/AIDS Strategy 1996–97 to 1998–99*. This enhanced existing efforts by Australian, State and Territory Governments and community based organisations in reducing the transmission of blood borne viruses. The most important of these existing initiatives were NSPs, which since their establishment in the late 1980s have proven to be one of the most cost effective measures implemented by governments to reduce drug related harm. An estimated 21,000 hepatitis C infections have been prevented by making sterile equipment available through NSPs<sup>xxii</sup>. Savings from the number of HIV and hepatitis C cases avoided is estimated to be at least \$2.4 billion<sup>xxii</sup>.

In 1999–2000 Australia became a world leader in its strategic response to hepatitis C through developing the first *National Hepatitis C Strategy 1999–2000 to 2003–2004*. Actions taken within the framework of the four year strategy contributed to:

- increased awareness of hepatitis C as a serious public health problem;
- establishment of a partnership approach as a firm foundation for action;
- a better understanding of the virus and its transmission;
- making affordable improved treatments available, with better clinical outcomes for people with hepatitis C;
- development of key documents such as A Model of Care for the Management of Hepatitis C Infection in Adults, National Hepatitis C Testing Policy and National Hepatitis C Resource Manual;
- increased research activity in relation to hepatitis C;
- significant hepatitis C education initiatives targeted to health care workers; and
- development of resources for people with or at risk of hepatitis C.

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<sup>4</sup>For the purposes of this calculation, costs were calculated over a nominal ‘lifetime’ of 50 years for each case.

## 2.7 The review: Main outcomes and recommendations

In February 2002, the Federal Minister for Health and Ageing requested an independent review of the *National Hepatitis C Strategy 1999–2000 to 2003–2004*.

The review found that the *National Hepatitis C Strategy 1999–2000 to 2003–2004*:

- established a firm partnership between people with or at risk of hepatitis C, governments at all levels, and medical, scientific and health care professionals, all of whom acknowledge the need to work together in a collaborative, non-partisan manner; and
- contributed to an increased awareness of hepatitis C as a serious public health problem.

Despite this, the review also found the National Hepatitis C Strategy did not succeed in controlling the hepatitis C epidemic. Key problems with the *National Hepatitis C Strategy 1999–2000 to 2003–2004* which the review highlighted include:

- absence of an implementation plan and performance indicators for monitoring the National Hepatitis C Strategy; and
- inadequate research and surveillance into hepatitis C.

In response to the review, and in recognition of continuing high rates of hepatitis C transmission, the Australian Government:

- reiterated its commitment to the partnership approach which has been so central to Australia's response; and
- undertook to develop a second National Hepatitis C Strategy to build on the successes of the previous strategy.

## 2.8 The current context

A number of challenges are inherent in preventing the transmission of hepatitis C and supporting and treating those affected by the virus. Implementation of this National Hepatitis C Strategy occurs in the context of:

- an already high level of hepatitis C prevalence in the community. This makes it more difficult to prevent further transmission, especially as hepatitis C is highly infectious in drug injecting contexts;
- low levels of awareness among the general community of what hepatitis C is and who is at risk;
- the poor health already experienced by at risk groups such as people who inject drugs and Aboriginal and Torres Strait Islander people who engage in risk behaviours;
- difficulties in developing intervention strategies due to the diversity of the population living with hepatitis C, and the social marginalisation experienced by many with or at risk of hepatitis C;
- high levels of discrimination and stigma against many people with or at risk of hepatitis C, especially against people who inject drugs, add a further burden to the physiological aspects of this major epidemic;
- barriers to accessing treatment for hepatitis C such as discrimination and peoples' perceptions and experiences in relation to the side effects of treatment;

- lack of awareness among people with hepatitis C that treatment can lead to an eradication of hepatitis C related symptoms and reduce the likelihood of further transmission;
- co-morbidity of hepatitis C with other conditions; and
- high rates of hepatitis C in custodial settings, continued hepatitis C transmission and lack of access to preventive measures and treatment within these institutions.

Chapter 3 of this National Hepatitis C Strategy details the responses to these and other challenges.

## **2.9 The partnership approach**

The partnership approach is a fundamental component of this National Hepatitis C Strategy. It recognises that collaborative efforts involving all levels of government, community based organisations, the medical, health care, research and scientific communities and people with or at risk of hepatitis C are required for an effective national response. Such an approach is especially important given the marginalisation experienced by many people with or at risk of hepatitis C.

This National Hepatitis C Strategy defines partnership as an inclusive approach which:

- shares a commitment to the aims of the National Hepatitis C Strategy;
- values and utilises the diversity of views and expertise within the partnership;
- fosters continuing dialogue between partners;
- collaborates, consults and coordinates across diverse sectors; and
- empowers and supports partnership members in fulfilling their roles and responsibilities, as outlined in Chapter 4 of this National Hepatitis C Strategy.

The partnership is based on a commitment to consultation and joint decision making. It involves an assurance from all parties to work as equals in addressing the challenges posed by hepatitis C. The approach acknowledges and values the specific expertise which each partner contributes to the national response.

The partnership approach also acknowledges that collaboration must occur across the whole of government, including health, justice, housing, welfare, income support, education and community service agencies.

## **2.10 Coordinated approach with other strategies**

Effective implementation of this National Hepatitis C Strategy demands coordination with a range of other national health strategies which bear upon the health and wellbeing of people with or at risk of hepatitis C. Among these strategies are:

- National Drug Strategy 2004–2009: as people who inject drugs are at high risk of hepatitis C infection, this National Hepatitis C Strategy must forge strong linkages with the National Drug Strategy to ensure people who inject drugs have access to both demand and harm reduction measures as a means of reducing risk. Linkages will be strengthened between advisory structures, such as the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH) and the Australian National Council on Drugs (ANCD) through mechanisms such as common membership. The MACASHH will also participate in forums and events auspiced by the ANCD and Intergovernmental Committee on Drugs where possible;

This National Hepatitis C Strategy will also seek to contribute to implementation of the National Drug Strategy Aboriginal and Torres Strait Islander Complementary Action Plan 2003–2006 , and in particular Key Result Area 2 – ‘Whole of government effort in collaboration with community based organisations to implement, evaluate and improve comprehensive approaches to reduce drug related harm’;

- National HIV/AIDS Strategy 2005–2008: The National HIV/AIDS Strategy also recognises the need for the community and all levels of government to be involved in reducing the transmission of blood borne viruses. The MACASHH will advise on health promotion activities for priority groups such as people who inject drugs who are at risk of both hepatitis C and HIV infection. Co-infection with hepatitis C and HIV is also a basis of significant overlap between the two strategies. As stated previously, people co-infected with hepatitis and HIV often have poorer health outcomes and heightened care requirements, such as issues with drug interactions. Strong collaboration in the design and delivery of education messages and treatment, care and support services is necessary in achieving optimal health outcomes for these people;
- National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy: This strategy outlines a national approach to preventing the spread of blood borne viruses in Aboriginal and Torres Strait Islander communities. It is important to recognise that this strategy is complementary to the National Hepatitis C Strategy rather than being a substitute strategy for this identified population. This National Hepatitis C Strategy recognises Aboriginal and Torres Strait Islander people who engage in risk behaviours as a priority group at risk of hepatitis C infection and is committed to working towards the goals and objectives of this strategy. Priority areas include prevention, treatment, care and support, workforce issues, research and data collection. This work will be progressed through the MACASHH;
- National STIs Strategy 2005–2008: The National STIs Strategy shares with the Hepatitis C Strategy a population based approach to disease prevention. Where possible, and avoiding misinformation, hepatitis C prevention messages will be incorporated into STI prevention activities and vice versa. This is especially important for Aboriginal and Torres Strait Islander people, who may be at heightened risk for both diseases, and because the Indigenous sexual health workforce is responsible for both STI and blood borne virus prevention.
- National Aboriginal and Torres Strait Islander Health Strategic Framework: This framework outlines the ways in which Aboriginal and Torres Strait Islander primary health care services and mainstream health services will work together to improve the health of Aboriginal and Torres Strait Islander people. The National Hepatitis C Strategy will seek to ensure Aboriginal and Torres Strait Islander communities are aware of hepatitis C and related issues, and can incorporate these where appropriate into planning and program development at the local level;
- National Health Workforce Strategic Framework: This framework commits to building a health workforce with the skills, competence and flexibility to meet the health needs of all Australians. This National Hepatitis C Strategy will seek to ensure that hepatitis C related issues are incorporated into relevant education and training initiatives developed under this framework;
- National Mental Health Plan: This plan includes the promotion of mental health and increasing service responsiveness as priority themes. This National Hepatitis C Strategy will seek to ensure health promotion and workforce development activities implemented as part of the

National Mental Health Plan recognise hepatitis C as a condition which may either cause poor mental health or exacerbate existing problems; and

- Healthy Horizons: A framework for improving the health of rural, regional and remote Australians: This National Hepatitis C Strategy will build on attempts under the Healthy Horizons framework to increase capacity of the rural workforce and develop flexible and coordinated services in rural and remote areas. This will ensure all people with or at risk of hepatitis C have access to prevention and treatment services, irrespective of where they live.

Coordination will involve ensuring the needs of people with or at risk of hepatitis C are included in the development and implementation of relevant initiatives. It will also ensure people with hepatitis C have full access to services funded through these initiatives.



# 3 Priority action areas

## 3.1 Prevention and education

Hepatitis C transmission is preventable. Preventive measures, through reducing rates of transmission of hepatitis C have considerable benefits for our community. Reduced transmission leads to lower prevalence of hepatitis C in the long term, thereby improving overall health outcomes and reducing the pressures on Australia's health care system which arise from hepatitis C infection.

Although there are already established prevention programs in Australia, the high number of new infections demonstrates the need to enhance and broaden those efforts. For many people living with or at risk of hepatitis C their only contact with the health system is through primary health care services. It is essential that opportunities for hepatitis C prevention and education in these services are utilised.

Prevention and education activities must be underpinned by a supportive environment. People with or at risk of hepatitis C may experience social exclusion which is compounded by other issues such as poverty, homelessness, unemployment, mental illness and incarceration. Such issues can make it difficult for people at risk to access hepatitis C prevention services, or make hepatitis C education and prevention a priority in their lives. The national response to hepatitis C will seek to ensure all people at risk, or that have been at risk in the past, have access to and are supported in the use of, hepatitis C education and prevention services, regardless of their social and economic circumstances.

Prevention activities must target the behaviours which place people at risk, and the settings where people may be exposed to infection. Such activities will include an expansion of proven interventions as well as investigation of other innovative measures. On a community wide basis it is also important to inform people about all the harms associated with drug use, as people may not be aware of the potential harms associated with injecting drug use.

As the greatest number of new infections are among people who inject drugs, many preventive interventions developed and implemented under this National Hepatitis C Strategy will focus on reducing the harm associated with injecting drug use. Harm reduction is one of the three elements (alongside demand and supply reduction) which underpin Australia's approach to drug use, as articulated in the National Drug Strategy 2004–2009. Initiatives under the auspices of the National Drug Strategy 2004–2009 include NSPs, peer education, drug substitution, diversionary programs and development of a comprehensive approach to dealing with drug use and related harms in custodial settings.

Other groups, such as people with medically acquired hepatitis C and people from CALD backgrounds, may be unaware of their hepatitis C status and require education about the virus and its risk factors. Education and increased awareness of the broader community is also important to encourage those at risk to undertake testing, to help prevent further increases in hepatitis C infection and to promote understanding of hepatitis C and its impact on those affected.

The involvement of people living with or at risk of hepatitis C is crucial to prevention and education efforts. Peer education has been proven internationally to be effective in reducing the transmission of blood borne viruses such as hepatitis C and HIV xxiii. People with or at risk



of hepatitis C have a unique understanding of the behaviours and contexts which place others at risk of infection. With appropriate training and support people living with or at risk of hepatitis C are best placed to communicate messages about reducing transmission to those who are either unaware of their hepatitis C status, or at risk of acquiring hepatitis C.

### Priority Action Areas

- increase public knowledge of hepatitis C and who is at risk, as well as encouraging preventive measures (including early testing and treatment) as recommended by the Senate Inquiry into Hepatitis C and the Blood Supply in Australia v;
- provide information about hepatitis C and promote a range of hepatitis C prevention strategies including access to clean injecting equipment through NSPs, drug substitution such as methadone, and drug treatment;
- continue to support and expand availability of and access to NSPs, and strengthen community understanding of the broad public health goals and achievements underpinning such programs;
- investigate strategies to prevent injecting drug use;
- continue to support pharmacies to act as secondary needle and syringe outlets, and to provide information about hepatitis C;
- strengthen the role of drug education and treatment programs and NSPs in hepatitis C prevention (including reducing the onset of injecting drug use and encouraging people dependent on drugs to seek drug treatment ) and referral to hepatitis C treatment;
- improve the responsiveness of primary health care services to people with hepatitis C, particularly those who inject drugs;
- train and support medical and allied health practitioners to provide education and counselling for people with or at risk of hepatitis C;
- support peer based drug user organisations to train and deliver peer education on the full range of hepatitis C risks, including education on transmission, blood awareness and individual preventive strategies;
- support Aboriginal and Torres Strait Islander primary health care services and mainstream health services to provide education and counselling on hepatitis C to Aboriginal and Torres Strait Islander people, as part of broader health promotion programs;
- support Aboriginal and Torres Strait Islander primary health care services to develop and implement hepatitis C education programs within a framework appropriate to their communities;
- encourage partnerships between Aboriginal and Torres Strait Islander primary health care services, peer based drug user organisations and research bodies in the development and delivery of harm reduction strategies tailored to Aboriginal and Torres Strait Islander people;
- establish a collaboration of State and Territory Governments to develop and implement hepatitis C education and prevention in custodial settings and encourage sharing models of care between jurisdictions;
- establish a collaboration between Australian and State and Territory Governments to ensure safe practices by industries engaging in skin penetration, consistent with Regulation of Infection Control in the Body Art Industry in Australia and New Zealand;

- develop methods of preventing hepatitis C transmission among marginalised populations, such as people who inject drugs who do not access NSPs, and the homeless;
- improve access to the means of preventing hepatitis C transmission in rural settings;
- support multicultural health services and mainstream health services to provide education and counselling to people of CALD backgrounds, as part of broader health promotion programs;
- increase awareness among people from CALD backgrounds of available harm reduction strategies;
- encourage implementation of the Infection Control Guidelines, especially in health care and custodial settings;
- encourage implementation of the National Code of Practice for the Control of Workplace Related Exposure to Hepatitis and HIV (Blood Borne) Viruses 2003;
- encourage hepatitis A and hepatitis B vaccinations for people with or at risk of hepatitis C, especially in custodial settings;
- increase awareness of hepatitis C and preventive measures among young people; and
- train and support youth workers, school teachers and other school staff such as Aboriginal Liaison Officers to provide education for young people about hepatitis C and the serious risks of injecting drug use, especially in relation to hepatitis C transmission.

### **3.2 Diagnosis, treatment and support**

Testing is the primary tool for diagnosing and assessing the prognosis for people with chronic hepatitis C. The diagnostic event shapes how people with hepatitis C understand their infection. It is essential that diagnosis is handled sensitively and that all patients being tested receive information about hepatitis C and the support services available to them. The National Hepatitis C Testing Policy has been developed to provide advice to government, health professionals, industry, people with hepatitis C and the wider community, about matters associated with testing. It emphasises that testing should be voluntary, and be accompanied by pre and post test counselling and informed consent. Further dissemination of this policy is required, to encourage appropriate hepatitis C testing practices.

Improving treatments and increasing their availability is central to the response to hepatitis C infection in Australia. With an estimated 16,000 new infections each year, the demand for treatment is likely to increase substantially. The efficacy of treatment is improving and it is now possible to cure hepatitis C completely in around half of the people being treated. Cure not only improves quality of life for those who successfully undergo treatment, but also reduces the risk of passing the virus on to others. These improved outcomes need to be more widely communicated to people with hepatitis C.

Only an estimated 1 per cent of people living with hepatitis C are accessing this treatment vii. Access to treatment is constrained by:

- eligibility criteria;
- lack of knowledge of improved treatments and outcomes;
- the side effects of treatment;
- the geographic and physical location of treatment services;

- co-morbidity with other conditions;
- limited infrastructure and staff to deliver services, for example in rural and remote areas or in Aboriginal and Torres Strait Islander primary health care services;
- cultural and language barriers;
- homelessness;
- financial losses from reducing hours of work in order to undertake treatment;
- incarceration; and
- experiences of discrimination in health care settings.

This National Hepatitis C Strategy will seek to increase the availability of testing and treatment services through general practitioners and other primary care providers. In doing so, this National Hepatitis C Strategy will build on current Australian Government initiatives such as the Strengthening Medicare package. The Strengthening Medicare package seeks to increase the accessibility of primary care services by:

- providing a safety net which will meet 80 per cent of out of pocket medical costs for all individuals and families, once a threshold is met; and
- increasing the number of health professionals working in the community, especially in outer metropolitan, rural and remote areas.

This National Hepatitis C Strategy recognises that people who inject drugs often experience barriers to accessing primary health care services, which can lead to multiple chronic health problems. Seeking testing and treatment for hepatitis C therefore may be a low priority for this group. Improved responsiveness of primary health care services allows people who inject drugs to address their most pressing health needs, thereby making them more receptive to messages about the prevention and treatment of hepatitis C. It is also important to provide additional support mechanisms for people who inject drugs, as they may have difficulty adhering to treatment regimens.

#### Priority action areas

- further disseminate and develop an implementation plan for the National Hepatitis C Testing Policy;
- promote the improved efficacy and benefits of treatment to people with hepatitis C, and primary health care providers;
- investigate and address barriers to the uptake and completion of treatment, particularly in marginalised populations;
- investigate alternative measures to care for and support people with hepatitis C who are not eligible for treatment or do not respond to treatment, and for people who do not access mainstream services;
- review access and eligibility criteria for hepatitis C treatments through the Pharmaceutical Benefits Scheme;
- encourage application of the Model of Care for the Management of Hepatitis C Infection in Adults in all jurisdictions, especially in custodial settings;

- support services dealing with people at risk, such as drug and alcohol services, peer based drug user organisations and NSPs, to provide information and referral to hepatitis C testing and treatment;
- investigate measures to increase the role of general practitioners and other health care providers in prescribing and monitoring treatment for people with hepatitis C, especially where access to specialist services is limited;
- expand and improve access to hepatitis C testing, treatment and counselling services, as well as education and information for people in custodial settings;
- develop national guidelines for the management and care of people living with or at risk of hepatitis C infection in custodial settings;
- enhance the capacity of Aboriginal and Torres Strait Islander primary health care services and mainstream health services to promote and provide treatment and support to Aboriginal and Torres Strait Islander people with hepatitis C;
- enhance the capacity of primary health care providers to provide information, support and referral to people from CALD backgrounds; and
- ensure culturally appropriate information about treatment options is available for people from CALD backgrounds.

### **3.3 Surveillance**

Surveillance mechanisms are crucial for monitoring the prevalence and incidence of hepatitis C in our community, to identify people at risk and allow effective targeting of prevention and treatment programs. Surveillance also provides data to assist in evaluation of interventions and increase knowledge of the long-term consequences of hepatitis C infection.

The current surveillance system is based largely on prevalence data from sentinel populations in which a high prevalence is expected (for example people attending NSPs) and in which a low prevalence is anticipated (for example blood donors) for hepatitis C. Notifications of newly acquired hepatitis C infections to the National Notifiable Diseases Surveillance System underestimate the true incidence of hepatitis C, while notifications of unspecified or chronic cases underestimate the burden of disease attributable to hepatitis C. For these reasons, the response to hepatitis C has thus far relied on modelling of the incidence and prevalence of the disease.

Improved surveillance mechanisms are required to provide more information on population level prevalence and incidence to inform implementation and monitoring of this National Hepatitis C Strategy.

#### **Priority action areas**

- independently evaluate the Australian Hepatitis C Surveillance Strategy;
- in light of recommendations of the above evaluation, support and enhance appropriate national hepatitis C surveillance mechanisms;
- establish surveillance systems which can more effectively monitor the rates and risk factors of new infection, which may include sentinel sites for hepatitis C surveillance;
- promote standardisation of surveillance data collection across all jurisdictions;

- ensure existing surveillance mechanisms can accurately identify Aboriginal and Torres Strait Islander status on all reports, and explore surveillance models which better target Aboriginal and Torres Strait Islander populations at risk; and
- commission new modelling of hepatitis C prevalence and incidence data.

### 3.4 Research

Research provides an evidence base for the development of public policy and programs which are responsive to the evolving needs of people with or at risk of hepatitis C. Regular interactions between researchers, health care professionals, community based organisations, affected communities and policy makers will ensure the use of up to date evidence in policy and practice.

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

Despite an increased understanding of hepatitis C over the last decade, further research is required into the factors influencing prevention, treatment and support for people with or at risk of hepatitis C. To accommodate the diverse circumstances and contexts in which the hepatitis C virus is transmitted, a balance is needed between strategic research to guide the national response (including policy formulation and health promotion interventions) and local research which investigates unique contexts and circumstances.

#### Priority action areas

- develop a set of research priorities for hepatitis C which address the epidemiological, cultural, economic and social aspects of the disease, including barriers to seeking treatment;
- hold an annual roundtable consultation on research priorities for HIV/AIDS, hepatitis C and sexually transmissible infections;
- further integrate a focus on hepatitis C into research by the National Centres for HIV Research and the National Centres for Drug and Alcohol Research, strategic and investigator driven research via the National Health and Medical Research Council, Australian Research Council, State based research programs and other directly funded research;
- develop and maintain links between researchers, health professionals, community based organisations, affected communities and policy makers to ensure the uptake of research into policy and practice by publishing research summaries, presenting at key conferences and holding regular forums and meetings;
- support affected communities to undertake peer driven research projects in relation to the needs and issues for people with or at risk of hepatitis C;
- foster research partnerships which increase the involvement of Aboriginal and Torres Strait Islander people and their representative organisations in setting research priorities and conducting hepatitis C related social, behavioural and epidemiological research;
- facilitate research on barriers to the uptake of hepatitis C prevention and treatment services;
- facilitate the systematic documentation of discrimination against people with hepatitis C, and investigation of the underlying factors leading to discrimination;
- facilitate research into risk factors, treatment and prognosis issues specific to people who inject drugs, Aboriginal and Torres Strait Islander people, people in custodial settings and other marginalised communities;

- facilitate research into effective treatments and therapies and access to these treatments; and
- facilitate the active involvement of affected communities in the design and implementation of research projects.

### **3.5 Health maintenance, care and support for people with hepatitis C**

Many factors which affect the health and wellbeing of people with hepatitis C do not fall within the ambit of specialist hepatitis C clinical services. The majority of people with hepatitis C do not receive treatment and depend on a range of other clinical and social supports to maintain their health.

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 care and support needs expressed in this National Hepatitis C Strategy.

Hepatitis C can affect all areas of life, including personal relationships and employment. Supporting people with hepatitis C is crucial at all stages of service provision, including counselling during pre and post testing, during treatment and on an ongoing basis vi.

Services and organisations which support people with hepatitis C include general practitioners, hepatitis councils, peer based drug user organisations, haemophilia foundations, advocacy groups for people with medically acquired hepatitis C, liver clinics, health services in custodial settings, NSPs, community health centres, drug and alcohol services, mental health services, Aboriginal and Torres Strait Islander primary health care services, youth services and specialist health services for people from CALD backgrounds. There is a particular need to ensure those delivering services in these contexts have the knowledge, skills and resources to deliver appropriate services to people with hepatitis C.

In increasing care and support for people living with hepatitis C, this National Hepatitis C Strategy is assisted by recent changes to the Medicare Benefits Schedule. For example the Enhanced Primary Care (EPC) program provides scope for general practitioners to better manage specific diseases such as hepatitis C. EPC provides support for interdisciplinary coordinated care of people with chronic conditions and complex needs. Patients being managed under an EPC care plan can also utilise new Medicare items which provide access to a limited number of allied health and dental services each year.

#### **Priority action areas**

- encourage general practitioners, in caring for patients with hepatitis C, to develop multidisciplinary care plans and refer eligible patients to allied health and dental services;
- continue to assist organisations representing people with or at risk of hepatitis C to provide services, information and support;
- encourage local partnerships between organisations representing people with or at risk of hepatitis C and Aboriginal and Torres Strait Islander primary health care services;
- improve referral mechanisms and encourage collaboration between general practitioners, specialist clinics and other health and welfare services in relation to the clinical and psycho-social needs of people with hepatitis C;

- encourage people with hepatitis C to access existing allied health, dental and support services;
  - increase the involvement of general practitioners in hepatitis C care and support, for example through expanding the participation of GPs in liver clinics;
- continue to develop culturally appropriate resources which assist people living with hepatitis C to improve and maintain their own health;
- increase the involvement of nurses and other health care professionals in ongoing monitoring and follow up of patients with hepatitis C;
- develop and implement chronic disease management strategies which incorporate changes to diet, exercise and alcohol intake;
- establish and maintain links with other national initiatives in relation to drug use, rural health, Aboriginal and Torres Strait Islander health, multicultural health, mental health and chronic disease management, to ensure people with hepatitis C receive holistic, non judgemental care and support; and
- review and address barriers to accessing hepatitis C related information and support in rural and remote areas and custodial settings.

### **3.6 Workforce development**

A workforce comprised of people with up to date knowledge about transmission risks, diagnosis, treatment and care for people with hepatitis C is essential to minimising the impact of the virus. The review of the National Hepatitis C Strategy 1999-2000 to 2003-2004 found existing health services have limited capacity to carry the current treatment load and noted development of the health workforce is critical to increasing the uptake of treatment.

The National Hepatitis C Testing Policy acknowledges the need to continue education programs for health care professionals involved in the testing and care of people with hepatitis C. In particular, these programs should be designed to develop professionals' skills in identifying people at risk of infection and be developed and implemented with input from people with hepatitis C. Such programs should also encourage non judgemental attitudes to people with hepatitis C, regardless of the mode of transmission.

General practitioners and other health care providers, such as drug and alcohol services, sexual health clinics and adolescent health services, have responsibility for diagnostic testing, conducting adequate pre and post-test counselling and providing information, support and referral for people with hepatitis C. In Aboriginal and Torres Strait Islander communities, the sexual health workforce has prime responsibility for responding to hepatitis C, and requires further development to diversify into this area.

People outside the health sector, such as parents, education departments and teachers also have a vital role in informing children and young people about issues relating to hepatitis C transmission.

#### **Priority action areas**

- develop national standards (including core competencies) on educating health care professionals about hepatitis C;
- improve the knowledge and skills of health professionals in dealing appropriately with people with or at risk of hepatitis C;

- improve the knowledge and skills of workers outside the health sector, such as youth workers, teachers, welfare workers and custodial staff around hepatitis C related issues;
- provide specific training for staff and volunteers in NSPs, and other workers in regular contact with people with or at risk of hepatitis C, to enable them to provide health and referral information;
- encourage appropriate training for healthcare professionals in relation to pre and post testing counselling;
- integrate training about hepatitis C and related issues into undergraduate curricula for the medical, nursing and allied health workforces;
- offer specific training regarding discrimination and confidentiality via universities, clinical schools and other training settings;
- ensure both mainstream and Aboriginal and Torres Strait Islander health workers are trained to deliver culturally appropriate interventions to Aboriginal and Torres Strait Islander people with or at risk of hepatitis C;
- ensure all health workers are trained to deliver culturally appropriate interventions to people from CALD backgrounds with or at risk of hepatitis C; and
- incorporate information about hepatitis C and related issues into existing health education curricula offered by schools.

### **3.7 Addressing discrimination and stigma**

Discrimination and stigma have a major impact on the lives of many people with or at risk of hepatitis C. Inquiries by the New South Wales Anti-Discrimination Board in 2001 and the Senate Community Affairs References Committee in 2004v both found ‘hepatitis C is a highly stigmatised condition and that discrimination against people with hepatitis C is rife xiv.

A person whose hepatitis C status becomes known may experience discrimination within social networks, local businesses, sporting groups, workplaces, child care facilities, and within institutions such as schools, hospitals, health centres, dental clinics and within custodial settings.

The underlying causes of such discrimination are varied but often result from either an unfounded fear of infection or the close link hepatitis C has with injecting drug use—a highly stigmatised behaviour.

For Aboriginal and Torres Strait Islander people, hepatitis C related discrimination is compounded by a level of access to appropriate health services which is already lower than the general population. People from CALD backgrounds, homeless people, those with mental health problems, and those in custodial settings may also suffer from pre-existing discrimination which is exacerbated by their hepatitis C status.

Eliminating discrimination against people with hepatitis C, or who are assumed to have hepatitis C, is important both as a human rights issue in itself and because such discrimination affects the mental and physical health of individuals xxiv. The Australian Government and all State and Territory Governments have enacted legislation which makes it unlawful to discriminate against people with hepatitis C. At the same time anecdotal evidence suggests the cases of discrimination against people with hepatitis C far outweigh those officially lodged under anti-discrimination instruments.



The fear of stigma and discrimination makes some people at risk reluctant to be tested for hepatitis C. Avoiding testing limits the possibility of considering appropriate treatment options and undertaking actions to self-manage their health.

People who inject drugs may already have minimal contact with the primary health care system due to the stigma and discrimination experienced when attempting to access health and social services. People with hepatitis C who inject drugs are even more likely to avoid seeking support and care from health care professionals because they believe their hepatitis C status will cause further stigma and discrimination.

### Priority action areas

- develop and implement activities which raise awareness in the community of hepatitis C and its personal, social and economic consequences;
- increase understanding of the nature and extent of hepatitis C related discrimination and the strategies which would prevent discrimination from occurring;
- develop targeted anti-discrimination education strategies for healthcare and employment settings;
- support organisations representing people with or at risk of hepatitis C to advocate for their needs, including in issues related to discrimination;
- ensure individuals with hepatitis C have the knowledge, skills and support to seek redress when they have, or may have experienced, discrimination; and
- facilitate effective partnerships between hepatitis C prevention, treatment and support services and anti-discrimination agencies such as community legal centres, health care complaint agencies and State and Territory Equal Opportunity Commissions or Discrimination Commissions.

# 4 Supporting structures

Implementation of this National Hepatitis C Strategy will take place at a number of levels. 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.

## 4.1 Australian Government

The Australian Government leads the national effort to control hepatitis C and has specific responsibility to:

- facilitate national policy formulation and coordinate hepatitis C related policies of Australian Government and State and Territory Government agencies, in conjunction with the other partners. This includes development of this National Hepatitis C Strategy and associated implementation plan, and related strategies such as the National HIV/AIDS Strategy, National Drug Strategy and the National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy;
- develop and implement national programs such as the 2003–04 Hepatitis C Education and Prevention Initiative and the 2003–04 Supporting Measures for Needle and Syringe Programs to provide hepatitis C education and referral to hepatitis C treatment;
- subsidise treatment for hepatitis C through the Pharmaceutical Benefits Scheme;
- administer funding to State and Territory Governments and community based organisations;
- support National Hepatitis C Strategy related research and research infrastructure through the National Centres for HIV Research;
- monitor and analyse the epidemic across Australia;
- establish public policy and legislative frameworks across government which are consistent with the aims and objectives of this National Hepatitis C Strategy;
- regulate medicines, blood and medical devices, including tests for the diagnosis and monitoring of blood borne viruses;
- promote international cooperation in relation to harm reduction; and
- provide secretariat and policy-support functions for national committees.

The role of the Department of Immigration and Multicultural and Indigenous Affairs in pre-arrival testing is recognised, however it is not included in the focus of this National Hepatitis C Strategy.

## 4.2 Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH)

MACASHH is the key body providing independent and expert advice to the Minister for Health and Ageing on policies and national strategies in relation to HIV/AIDS, sexually transmissible infections (STIs) and viral hepatitis. This advisory structure consists of the overarching MACASHH plus three expert subcommittees: the HIV/AIDS and STIs Subcommittee, Hepatitis C Subcommittee and Indigenous Australians' Sexual Health Committee.

The overarching MACASHH is responsible for:

- establishing alliances between those working in hepatitis C and HIV/AIDS prevention and the reduction of drug related harm;
- coordinating a whole of government response to hepatitis C and HIV/AIDS, including engagement with relevant agencies such as those responsible for education, housing, income support, legislation and justice;
- consulting and liaising with other stakeholders, public health advisory bodies, the research sector and relevant peak community based organisations; and
- working closely with the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases to develop and implement effective strategies, policies and programs to address HIV/ AIDS, hepatitis C and other viral hepatitis infections, Indigenous sexual health and STIs.

### **4.3 Hepatitis C Subcommittee of MACASHH**

The Hepatitis C Subcommittee provides specialist advice to inform the Australian Government's response to hepatitis C and other viral hepatitis infections, including identifying emerging issues and how they may be addressed. The membership of the subcommittee reflects the partnership approach, consisting of experts from relevant medical specialities, general practice, non-government partners, public health, health promotion, research and evaluation, and people with hepatitis C.

### **4.4 Indigenous Australians' Sexual Health Committee**

The Indigenous Australians' Sexual Health Committee (IASHC) provides specialist advice to inform the government's response to sexual health issues and blood borne viruses within Aboriginal and Torres Strait Islander communities. IASHC membership also reflects the partnership approach. IASHC is responsible for development of the National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy and also provides input into development of this National Hepatitis Strategy. This is to ensure the specific risks and needs of Aboriginal and Torres Strait Islander communities are incorporated into the national response to hepatitis C.

### **4.5 State and Territory Governments**

State and Territory Governments have a pivotal role in implementing this National Hepatitis C Strategy within their respective jurisdictions. This is mainly through Health Departments which are responsible for the provision of health services through hospitals, community health centres, drug and alcohol services, mental health services and prisoner health services. Other agencies such as education and justice departments also need to be involved in the response to hepatitis C.

The particular responsibilities of State and Territory Governments include to:

- implement this National Hepatitis C Strategy at the jurisdictional level, in collaboration with community based organisations;
- establish State and Territory hepatitis C strategies, including prevention, information, treatment and care and support plans;

- establish advisory forums with a membership that reflects the partnership in their jurisdiction;
- establish public policy and legislative frameworks consistent with the aims and objectives of this National Hepatitis C Strategy;
- investigate, analyse and monitor the epidemiology of hepatitis C within their jurisdiction;
- develop, deliver and evaluate a range of services, including public hospital services, NSPs, health promotion, school based health education, corrective health services and care and support services provided by public and community based organisations;
- provide workforce infrastructure and professional development and training for health professionals in the hepatitis C area, including those working in Aboriginal and Torres Strait Islander primary health care services;
- provide preventive programs and treatment services in custodial settings;
- participate in relevant national forums;
- ensure effective intersectoral cooperation between State and Territory and Local Government agencies;
- ensure resources are allocated in accordance with the priority areas expressed in this National Hepatitis C Strategy; and
- measure and report on implementation of this National Hepatitis C Strategy against agreed performance indicators within their jurisdiction.

#### **4.6 Intergovernmental Committee on HIV/AIDS, Hepatitis C and Related Diseases (IGCAHRD)**

The Intergovernmental Committee on HIV/AIDS, Hepatitis C and Related Diseases (IGCAHRD) provides a forum for regular Australian Government, State and Territory and community liaison on policy and programs. IGCAHRD comprises representatives of the eight State and Territory Health Departments, the Australian Government, representatives from community based organisations and HIV/AIDS and hepatitis C affected communities. IGCAHRD reports to the National Public Health Partnership (NPHP) through the Communicable Diseases Network of Australia (CDNA).

NPHP is responsible for identifying and developing strategic and integrated responses to public health priorities in Australia, one of which is communicable disease control. CDNA, a subcommittee of NPHP, provides national leadership and coordination on communicable disease surveillance, prevention and control to minimise the impact of communicable diseases in Australia.

IGCAHRD is responsible for coordinating efforts under this National Hepatitis C Strategy, the National HIV/AIDS Strategy, National STIs Strategy and the National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy. The committee will provide expert advice and leadership on implementation of the Strategies and will collaborate with MACASHH and its Subcommittees in National Hepatitis C Strategy monitoring and evaluation. Collaboration will be facilitated by cross membership between, and community representation on, both bodies.

Given the shared responsibility of IGCAHRD and the Intergovernmental Committee on Drugs to reduce drug related harm, a joint IGCAHRD/IGCD committee will be reconstituted during the life of this National Hepatitis C Strategy.

#### **4.7 Local Government**

People with hepatitis C require services planned and delivered at the local level, and local governments are involved in a wide range of services which care for and support people with or at risk of hepatitis C infection.

Local governments are responsible for urban planning and development, which affects for example the location and operation of NSPs. The principles and priorities expressed in this National Hepatitis C Strategy should be reflected in these planning processes.

Local governments may also be responsible for regulating the skin penetration industry.

To ensure effective service delivery to people at risk of or living with hepatitis C, targeted work must be done with local governments. They will be encouraged to become involved in implementation of this National Hepatitis C Strategy through developing and maintaining partnerships at the local level. Where appropriate, activities at this level will be monitored and reported on by the respective State and Territory Governments.

#### **4.8 The community sector**

People with or at risk of hepatitis C and their community based organisations play a fundamental role in the development, implementation and evaluation of Australia's strategic response to hepatitis C. The community sector brings specific expertise to the partnership and ensures action which is informed by, and responsive to, the experiences of affected communities. Community based organisations participate in the response in a variety of ways, including to:

- advocate for the interests of people affected by hepatitis C in decision making and policy formulation;
- develop, deliver and evaluate policies and programs;
- participate in national and state and territory level committees such as MACASHH and ICGAHRD;
- contribute to the development of and participate in research and health promotion initiatives, including peer education, advocacy and social mobilisation projects; and
- contribute to the development and delivery of 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 and representative organisations.

#### **4.9 Research, medical, scientific and health care professionals**

Australia's research and scientific communities play an essential role in reducing discrimination, identifying preventive strategies which will reduce the transmission of hepatitis C, promoting treatment advances and providing treatment, care and support. Among the organisations responsible for contributing to the response to hepatitis C are the National Centres involved in HIV, hepatitis C and alcohol and other drug research. Other bodies such as

hospitals, laboratories, universities and private research agencies further contribute to the evidence base for hepatitis C policy and program development.

Associations of medical specialists (including general practitioners) and health care professionals also have a central function in contributing to public and professional education about hepatitis C and developing, implementing and maintaining best-practice standards for training.

#### **4.10 Ministerial Council on Drug Strategy (MCDS)**

The Ministerial Council on Drug Strategy (MCDS) is a national ministerial level forum responsible for developing policies and programs (such as the National Drug Strategy) to reduce the harm caused by drugs to individuals, families and communities in Australia. The MCDS is the peak policy and decision making body on licit and illicit drugs in Australia. It brings together Australian Government and State and Territory Ministers responsible for health and law enforcement, and the Australian Government Minister responsible for education. This is to ensure Australia has a nationally coordinated and integrated approach to reducing the substantial harms associated with drug use.

The MCDS is supported by the Intergovernmental Committee on Drugs (IGCD), which consists of senior health and law enforcement officials. MACASHH and IGCAHRD will forge links with the IGCD to ensure hepatitis C related issues are considered more broadly in illicit drug policy and program development.

#### **4.11 Australian National Council on Drugs (ANCD)**

The Australian National Council on Drugs (ANCD) is the principal non-government advisory body to the Australian Government on drug policy. The ANCD provides Ministers with independent expert advice on matters connected with licit and illicit drugs. It facilitates an enhanced partnership between governments and the non-government and community sectors in the development and implementation of policies and programs to redress drug-related harms.

Having a representative on the MACASHH who is also a member of the ANCD will ensure hepatitis C related policies and programs are informed by the most recent and evidence based approaches to reducing drug related harm. MACASHH will also engage with the other representatives from the alcohol and other drugs sector, including peak bodies and professional associations, to facilitate the incorporation of hepatitis C into the service delivery and training around alcohol and other drug issues more broadly.

#### **4.12 Parliamentary Liaison Group (PLG)**

The Parliamentary Liaison Group (PLG) was first established in 1985. It was established as an informal cross party forum to inform Members and Senators about HIV/AIDS and HIV-related developments. In 1996, the PLG's terms of reference were broadened to include related communicable diseases such as hepatitis C.

Under this National Hepatitis C Strategy, the PLG will be re-established and revitalised to ensure the Australian Parliament is informed regularly about the latest hepatitis C related developments in Australia and to provide a non-partisan forum for policy discussion.

State and Territory Governments are encouraged to develop similar mechanisms for fostering a cross party approach to hepatitis C related matters.



# 5 Monitoring and evaluation

Monitoring and evaluation mechanisms are required to ensure policy and practice is based on the best available evidence. Transparent and systematic monitoring and evaluation across all jurisdictions will ensure all activities contribute to the overall objectives of this National Hepatitis C Strategy.

The following measures will be used to monitor and evaluate this National Hepatitis C Strategy.

## 5.1 Implementation plan

A detailed implementation plan will be developed by the Australian Government, in consultation with State and Territory Governments and community based organisations through a joint MACASHH/ IGCAHRD forum. Progress against priority action areas will be monitored through regular reports to MACASHH, its subcommittees, IGCAHRD and other relevant bodies at the jurisdictional level.

This implementation plan will incorporate specific performance measures to help decision-makers and others assess how well this National Hepatitis C Strategy is being implemented. Performance measures and targets are also essential sources of insight for evaluation of the National Hepatitis C Strategy and should be disaggregated by variables such as Indigenous status. Such measures could include quantitative benchmarks such as:

- the trend in new hepatitis C infections;
- measures of the number of people with hepatitis C;
- increased awareness and knowledge around prevention amongst people with or at risk of hepatitis C;
- rates of sharing injecting equipment including needles, among injecting drug users and people attending NSPs;
- rates of prevalence among people who have been injecting drugs for less than three years;
- rates of treatment;
- effectiveness of treatment;
- increased awareness and knowledge about available treatment options amongst people with hepatitis C;
- rates of testing and treatment, and access to the means of hepatitis C prevention in custodial settings;
- number of GPs and other primary health care workers involved in shared care of patients with hepatitis C;
- number of GPs acting as S100 prescribers and the number of people treated by S100 prescribers; and
- trends in advanced liver disease, including transplantation.



## **5.2 Annual strategic issues workshop**

MACASHH and IGCAHRD will jointly convene an annual strategic issues workshop. The workshop will provide partners with information on emerging knowledge and practice in relation to the prevention and treatment of hepatitis C. The aim of this workshop is to decide priorities for the upcoming year and to identify activities which will address these priorities, in line with the overall objectives of this National Hepatitis C Strategy.

This workshop will also provide a key opportunity to create and sustain longer term links between the national strategies outlined in section 2.10

## **5.3 Reporting**

The Australian Government and State and Territory Governments will report annually to Health Ministers through MACASHH and IGCAHRD on activities and issues relevant to this National Hepatitis C Strategy.

Monitoring mechanisms which currently provide data and information on the effectiveness of hepatitis C activities include:

- the annual and other hepatitis C surveillance reports of the National Centre in HIV Epidemiology and Clinical Research and the National Centre for HIV Social Research;
- the annual and other communicable disease surveillance reports of the Communicable Diseases Network of Australia and New Zealand under the National Communicable Diseases Surveillance Strategy;
- State and Territory Governments’ monitoring and evaluation of this National Hepatitis C Strategy’s implementation in their jurisdiction;
- State and Territory Governments’ annual reporting on activities funded through the Hepatitis C Education and Prevention Initiative;
- data from the National Notifiable Diseases Surveillance System; and
- data on hepatitis C related expenditure and prescriptions through the Pharmaceutical Benefits Scheme.

Improving the hepatitis C surveillance system will also be crucial to ensure accurate data is available with which to evaluate this National Hepatitis C Strategy.

## **5.4 Evaluation framework for the National Hepatitis C Strategy**

An overall evaluation framework will accompany this National Hepatitis C Strategy, to enable greater planning for data collation, evaluations of individual initiatives and other research to support the evaluation of this Strategy as a whole. Development of this overall framework will be auspiced by MACASHH and specifically the Hepatitis C Subcommittee, with input from IGCAHRD. The framework will identify:

- key evaluation questions;
- data requirements;

- likely objectives of the evaluation;
- timing; and
- governance.

Responsibility for evaluation of individual programs or initiatives lies with the jurisdiction which funds or manages the program. It will be important to ensure all evaluations take place within a consistent national framework.

Specific evaluation outputs for the National Hepatitis C Strategy as a whole will include:

- MACASHH’s annual report to the Australian Government Minister for Health and Ageing on this National Hepatitis C Strategy’s implementation; and
- an independent, external mid term assessment of the efficiency, effectiveness and appropriateness of this National Hepatitis C Strategy and related activities, as part of the broader population health effort in Australia.



## 6 Glossary

### **acquired immune deficiency syndrome (AIDS)**

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

### **Asymptomatic**

an actively infected individual without symptoms at this stage of their infection.

### **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 bodily fluids which contain blood. Such transmission can result from sharing injecting equipment.

### **clinical research**

health research relating to individual consumers 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 consumers 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 or hepatitis B.

### **communicable disease**

a illness 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**

types of medicine that are not presently part of conventional medicine practice and may include: vitamins; minerals; nutritional supplements; herbal products; aromatherapy; and homeopathic products.

### **coordinated 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.

**cure, hepatitis C related**

the absence of hepatitis C specific RNA in the blood or liver of a person who has undergone treatment for hepatitis C and has been fully tested

**custodial settings**

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

**demand reduction strategies**

strategies that seek to reduce the desire for, and preparedness to obtain and use, drugs. These strategies are designed to prevent the uptake of harmful drug use and include abstinence orientated strategies aimed at reducing drug use.

**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.

**drug user organisations**

peer based organisations representing the needs and interests of people who use drugs illicitly.

**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.

**harm minimisation**

the primary principle underpinning the National Drug Strategy. 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/strategies**

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**

hepatitis is the name for several different illnesses which all cause the same problem: an inflamed (swollen or painful) liver. The liver is a vital part of the body. If it does not function properly, it can cause serious illness or sometimes even death. Drinking alcohol or taking drugs can cause hepatitis. It can also be caused by infectious viruses. The different types of virus are known by different letters-A, B, C, D and E-so the different forms of the disease are called 'hepatitis A', 'hepatitis B' and so on. Hepatitis B is a viral infection caused by the hepatitis B virus (HBV).

**hepatitis C virus**

an RNA virus transmitted through blood to blood contact.

**holistic**

a principle which affirms health as a state of complete physical, mental and social wellbeing. In Aboriginal and Torres Strait Islander communities this may encompass the wellbeing of the entire community.

**human immuno-deficiency virus (HIV)**

a human retrovirus that leads to AIDS.

**illicit drug**

a drug whose production, sale or possession is prohibited.

**Incidence**

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

**needle and syringe programs (NSPs)**

a public health measure to reduce the spread of blood borne viruses such as HIV and hepatitis C. NSPs provide a range of services which include the provision and disposal of injecting equipment, education and counselling and referral for people who inject drugs.

**peer education**

a process controlled, devised and implemented specifically by members of a peer group to address the education needs of other members of that peer group. An example is people who inject drugs developing and delivering messages about safe injecting practices to other people who inject drugs.

**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 proportion of individuals in a population having a disease.

**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.

**vaccine**

a preparation of antigenic material administered to induce a specific immunity to infection by the organism from which the antigenic material has been derived.

**viraemia**

the presence of a virus in the bloodstream of an infected individual.

**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.

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