

NSW Hepatitis C Strategy Environmental Scan 2007–2009

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SECTION 1

Overview

1.1 Goals

The *NSW Hepatitis C Strategy 2007–2009* provides a statewide strategic framework for the prevention and management of hepatitis C. The goals of this Strategy are to:

- Minimise the transmission of hepatitis C
- Improve the health status of people with hepatitis C
- Minimise the negative personal, social and economic impact of hepatitis C.

The goals will be achieved by:

- Implementing prevention and education strategies to reduce transmission of hepatitis C
- Providing equitable access to treatment, care and support services and increasing treatment uptake among people with hepatitis C
- Reducing discrimination, stigmatisation and marginalisation experienced by people with hepatitis C
- Improving the knowledge, skills and capacity of the workforce to meet the needs of people with or at risk of hepatitis C
- Improving monitoring, surveillance and research to better inform the NSW response to hepatitis C.

1.2 Guiding principles

The following principles guide the response to hepatitis C in NSW.

Harm minimisation

Harm minimisation refers to policies and programs aimed at reducing drug-related harm. Harm minimisation aims to improve health, social and economic outcomes for both the community and the individual. Harm minimisation encompasses a wide range of approaches from harm reduction through to drug supply reduction. This approach acknowledges the fact that some individuals will continue to participate in illegal behaviours, but does not condone drug use.

In relation to hepatitis C prevention and education, current harm reduction programs include interventions aimed at:

- ceasing or reducing injecting drug use
- drug substitution
- provision of sterile injecting equipment
- education about safe administration practices.

Health promotion

This Strategy has a strong focus on health promotion, which is the process of enabling people to increase control over, and to improve, their health, whether they are ill or not. Health promotion is a multi-strategic response, and encompasses individual, population and systemic interventions to:

- Create healthy public policy
- Develop personal skills
- Strengthen community action
- Create supportive environments
- Reorient health services.

A partnership approach

The partnership is a cooperative effort between all levels of government, the health sector, community organisations, researchers, the justice sector, and people with or at risk of hepatitis C. The partnership is based on a commitment to consultation and joint decision-making in all aspects of the response. This includes responding to hepatitis C in a non-partisan way.

The involvement of affected communities

The involvement of people with or at risk of hepatitis C and the organisations that represent them has been critical in the response to hepatitis C. This Strategy re-emphasises their input into the planning, delivery and evaluation of hepatitis C programs, services and policies. Hepatitis C services should take account of and respect the needs of people with or at risk of hepatitis C.

Transparency and accountability

The partners in NSW are committed to transparency and accountability with regard to budget, policy and strategy development and directions.

Transparent processes are essential for the maintenance of the partnership and the involvement of affected communities in current and future responses to hepatitis C.

An enabling environment

An enabling environment provides a social and legal environment that protects the rights of people with or at risk of hepatitis C, and encourages people with or at risk of hepatitis C to participate in the response to hepatitis C.

Access and equity

Access to hepatitis C services is inequitable and sub-optimal in some settings and for some populations. Services must be cognisant and responsive to the differing health and social needs which exist among people with or at risk of hepatitis C. This includes people who inject drugs, people from culturally and linguistically diverse backgrounds, Aboriginal people, people who live in rural areas, homeless people, people with a mental illness and incarcerated people.

Evidence based approach

Decisions about interventions to address hepatitis C should be made using the best available evidence and reasoning, including data and understandings drawn from quantitative and qualitative sources.

1.3 Priority populations at risk of hepatitis C infection

People who inject drugs

People who inject drugs are at high risk of contracting hepatitis C. Approximately 80 per cent of current infections are estimated to be due to unsafe injecting drug use practices. There are several difficulties in ensuring hepatitis C programs and services are accessible to this group including:

- The illicit nature of drug use
- The stigma and discrimination people who inject drugs experience or fear encountering, including within health care settings

- Poor levels of general health, compounded by other problems such as poverty, unemployment, poor access to housing.

This Strategy recognises that people who inject drugs are a diverse group. This Strategy places an emphasis on the importance of reaching young people who are at risk of commencing drug use. This Strategy also recognises that people in rural and remote areas may lack appropriate access to programs and services, as well as lack confidentiality when accessing services.

Aboriginal people who are at risk of hepatitis C infection

Reporting of Aboriginal status on hepatitis C notifications in NSW is less than 50 per cent (ranging from 26 per cent to 38 per cent in the period 2001 to 2004). However in 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.

Reporting of Aboriginal status on acute hepatitis C notifications in NSW is greater than 50 per cent (ranging from 58 per cent to 66 per cent in the period 2001 to 2004). While the numbers are relatively small (a total of 581 cases of acute hepatitis C were notified over the same period), they also show higher rates of hepatitis C reported in the Aboriginal population.

Taken together, the implications of these data for Aboriginal people in NSW are serious. They warrant continued vigilance and a concerted response from all levels of government and the community.

A range of factors has been identified as to why Aboriginal people are a priority population in this strategy. They include:

- A higher proportion of young people compared to the broader population
- Risks arising from high levels of incarceration
- Greater mobility compared to the broader population
- Levels of knowledge regarding hepatitis C
- Evidence that injecting drug use may be increasing in some Aboriginal communities
- Poorer access to health services including the NSP
- Evidence from the annual NSP survey suggesting that rates of shared use of injecting equipment are higher among Aboriginal participants.

This Strategy emphasises the importance of working with Aboriginal communities and organisations to address their hepatitis C needs.

People from culturally and linguistically diverse backgrounds

The relatively high hepatitis C prevalence in a number of culturally and linguistically diverse (CALD) population groups is associated with medical procedures in their country of origin. There is also some evidence of higher rates of re-using and sharing among people who inject drugs from a CALD background, poorer understanding of hepatitis C among CALD people who inject drugs and lower utilisation of the needle and syringe program and other hepatitis C services.ⁱⁱⁱ

CALD access to hepatitis C services is influenced by various factors including concerns about loss of confidentiality and privacy, community attitudes towards drug use and the negative profile of harm reduction services.

This Strategy is committed to working with CALD communities and organisations to address the needs of CALD people.

1.4 Settings

Rural settings

People with or at risk of hepatitis C in rural areas may have difficulty accessing programs and services. Programs and services are frequently based in urban areas which requires rural people travelling long distances to access these services. Particular attention should also be given to Aboriginal people, given approximately 40 per cent of the NSW Aboriginal population live in rural areas. This Strategy is committed to addressing the hepatitis C the needs of rural people with or at risk of hepatitis C.

Correctional settings

Hepatitis C prevalence is high among inmates of NSW Correctional Centres and detainees in Juvenile Justice Centres. Aboriginal people are at particular risk given their over-representation within Correctional Centres and Juvenile Justice Centres. Inmates and detainees do not have the same access to hepatitis C prevention and education services as the community, and access to hepatitis C treatment, care and support

may also be restricted for various reasons. This Strategy is committed to working to address the needs of incarcerated people with or at risk of hepatitis C.

1.5 Relationship to other strategies

The *NSW Hepatitis C Strategy 2007–2009* has been developed taking account of other key government strategies and policies.

National Hepatitis C Strategy 2005–2008

The *National Hepatitis C Strategy 2005–2008* provides the framework to guide the overall response to hepatitis C in Australia. It identifies seven priority areas, of which three will become the central focal points for action because they have the most potential for reducing transmissions 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
- Improving the current hepatitis C surveillance system.

The strategy recognises the importance of ensuring strong linkages with the *National Drug Strategy 2004–2009* to ensure people who inject drugs have access to both demand and harm reduction measures as a means of reducing risk.

National Aboriginal and Torres Strait Islander Sexual Health and Blood-Borne Virus Strategy 2005–2008

This strategy outlines a national approach to preventing the spread of blood-borne viruses in Aboriginal and Torres Strait Islander communities. The strategy is complementary to the *National Hepatitis C Strategy 2005–2008*. One of the four main aims of this strategy is to improve access to needle and syringe programs for Aboriginal people.

The NSW Department of Health has developed the *NSW HIV/AIDS, STI and Hepatitis C Strategies: Implementation Plan for Aboriginal People 2006–2009*. The plan provides directions consistent with the strategy and ensures coordination of hepatitis C and harm minimisation services to Aboriginal people in NSW.

NSW HIV Strategy 2006–2009

The *NSW HIV Strategy 2006–2009* outlines priorities for the response to HIV/AIDS in NSW. The strategy recognises preventing HIV transmission among people who inject drugs as a priority. The NSW Needle and Syringe Program is identified as the key strategy to prevent HIV transmission among people who inject drugs.

1.6 Funding

The NSW Government and the Australian Government share responsibility for funding the response to HIV/AIDS, STIs and hepatitis C in NSW. This funding is provided in accordance with the priorities and directions established by the National and NSW Hepatitis C HIV/AIDS, and STI Strategies.

During 2006/2007, the NSW Department of Health will allocate dedicated funding of approximately \$4.5 million for hepatitis C education and prevention programs and strategies to support access to hepatitis C clinical services. In addition, the Department will allocate \$13.6 million to the NSW Needle and Syringe Program and other programs for the prevention of blood borne viruses among people who inject drugs.

In recognition of the very high projected costs for future hepatitis C clinical services, the Department makes available funding for these services through its general allocation of funds to Area Health Services.

Australian Government

Funding for hepatitis C programs is derived from a number of sources. Program funding provided to NSW by the Australian Government includes:

- Funding through the Australian Health Care Agreements for the provision of free hospital services
- An annual grant of approximately \$1.9 million for the implementation of the *National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Viruses Strategy*
- Funding of \$2.6 million over four years to 2006/2007 for the Hepatitis C Education and Prevention Initiative
- Funding of \$10.7 million over four years to 2006/2007 for needle syringe program access, education, counselling and referral into treatment.

Additionally, NSW benefits from Australian Government expenditure on national hepatitis C initiatives, including

national research funding and a new national allocation for improved surveillance for hepatitis C, and from the provision of hepatitis C treatment through the Pharmaceutical Benefits Scheme.

NSW Government

During 2005/2006, the NSW Government will invest \$10.9 billion in the provision of health care to the people of NSW. The NSW Department of Health utilises a Resource Distribution Formula to guide the allocation of funds to Area Health Services in order to achieve equity in funding across populations in accordance with population-based health needs. Incorporated within this funding formula are components reflecting acute inpatient, outpatient and other health service activity, including where delivered to patients with hepatitis C.

Additionally, the NSW Government makes available dedicated recurrent funding of approximately \$3.8 million for the implementation of the NSW Hepatitis C Strategy and \$10.8 million for the prevention of blood borne viruses among people who inject drugs. As noted above, this funding excludes the cost of hepatitis C clinical services.

In 2004/2005, the NSW Government provided \$10.4 million for public sexual health services, for whom injecting drug users are an identified priority population.

Although an annual cost escalation contribution is applied to the dedicated Blood Borne Viruses and STI Funding Program, the budget for the Program has stabilised in real terms. It is not anticipated that significant new program funding will be made available to the Program during the course of this Strategy.

This stabilisation occurs in a context of significantly increased service demand. Despite declines in overall notifications and projected incidence, hepatitis C incidence and prevalence remains at an extremely high level and it is anticipated that treatment, care and support needs will grow significantly in the coming decade.

Accordingly, it is necessary that all services receiving dedicated hepatitis C funding services operate with the expectation that new dedicated funding will not be forthcoming. This requires that service planning be undertaken rigorously with a view to generating cost efficiencies and discontinuing services which are assessed to be of lower priority. Service planning should include a close consideration of the purpose for which dedicated hepatitis C funds are provided. Savings generated through this approach will be able

to be re-deployed to meet the demand for critical services and to fund innovative programs.

Proposals by Area Health Services and non-government organisations to significantly re-orient or discontinue services will require the approval of the Department through annual Area Health Service Funding Plan processes and through the re-negotiation of non-government organisation Funding and Performance Agreements. The Department will be guided by the priorities and directions established by the NSW Hepatitis C Strategy in reviewing the proposals.

In addition to dedicated BBV and STI Program funds allocated to AHSs and Non-Government Organisations (see below), the Department receives non-recurrent funding from the Australian Government for the implementation of specific initiatives. During 2006/2007 the Department received funding for three initiatives, being the implementation of the *National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy*, the Hepatitis C Education and Prevention Initiative and the Illicit Drug Diversion Initiative – Supporting Measures for Needle Syringe Programs. Funding from these programs is allocated in accordance with Deeds of Agreement between the Department and the Australian Government.

Area Health Services

As the overall funding to Area Health Service budgets incorporates a recognition of hepatitis C activity, dedicated hepatitis C funds are provided to strengthen capacity and are considered a contribution to the costs of hepatitis C service delivery. In particular the funding provided to Area Health Services via the national Hepatitis C Education and Prevention program is provided specifically to support education and prevention initiatives.

As a condition of dedicated BBV and STI Program funding, Area Health Services are required to submit to the Department an annual Funding Plan that specifies the proposed internal distribution of Program funds for the forthcoming financial year. Funding Plans are reviewed and assessed against Departmental criteria and are subject to formal Departmental approval. The *Guidelines for Completing Area Health Service AIDS and Related Program Funding Plans* provide instructions to Area Health Services on the completion of the Funding Plans and detail funding conditions for the dedicated BBV and STI Program.

Non-government organisations

During 2004/2005, funding of \$15.8 million was disbursed to hepatitis C, HIV/AIDS and STI community based and other non-government organisations (NGOs). This includes organisations with state-wide responsibilities as well as organisations with a focus on local service delivery or program implementation. The majority of funded NGOs address hepatitis C within programs and services which also address HIV/AIDS and sexual health. Responsibility for the funding and performance management of NGOs is largely devolved to Area Health Services which administer this program on behalf of the Department.

The NSW Department of Health *Operational Guidelines: Non-Government Organisations Grant Program* provide the policy framework for the administration of funding to NGOs within the health system.

Each NGO is funded on the basis of a formal Grant Application which specifies the objectives, activities, performance indicators and budget for the grant. Grants to NGOs are approved by the NSW Minister for Health. If a grant is approved, the information provided in the Grant Application forms the core of a Funding and Performance Agreement which is then legally executed. It is a requirement of this contractual arrangement that NGOs provide an annual financial acquittal and activity statement for each grant.

Hepatitis C in NSW and Australia

2.1 Natural history of hepatitis C

The hepatitis C virus is a major cause of viral hepatitis. Hepatitis means inflammation of the liver.

Hepatitis C is spread almost exclusively by the blood from an infected person getting into the bloodstream of another person. Only a small amount of blood is required to become infected. Recovery from hepatitis C does not confer immunity to reinfection, and there is no vaccine for hepatitis C.

Hepatitis C infection involves an initial or acute phase of infection, which usually lasts from two to six months. This phase is often asymptomatic with only about 20 per cent of cases having symptoms.

About 25 per cent of people infected with hepatitis C will clear the virus naturally, usually within the first 12 months. Antibodies to the virus persist after viral clearance, but decline over time. Exposure to the virus with subsequent clearance does not lead to immunity, and hepatitis C re-infection can occur following renewed exposure.

The remaining 75 per cent of people infected will develop a long-term or chronic infection. Of this group of people:

- 45 per cent will not develop serious liver damage
- 44 per cent will develop progressive mild to moderate liver damage
- 7 per cent will develop cirrhosis of the liver (after 20 years)
- 4 per cent will develop cirrhosis followed by liver failure or cancer (after 40 years).

Most people with chronic hepatitis C experience no symptoms until 10 to 20 years after initial infection. Symptoms of chronic infection commonly include fatigue or tiredness, lethargy, and flu-like symptoms. Symptoms can range from mild to severe.

Significant improvements have been made in the treatment of hepatitis C. Approximately 50 to 80 per cent of people receiving treatment with ribavirin and

pegylated interferon have a sustained viral response and are effectively cured.

2.2 Risk factors for transmission

Hepatitis C is transmitted through blood-to-blood contact. The primary risk factors and environments for transmission are:

- Injecting drug use
- Incarceration
- Skin penetration practices.

Other risk factors and environments include:

- Unsterile medical procedures
- Unscreened blood transfusions and blood products
- Occupational exposure
- Vertical transmission
- Household contacts
- Sexual contact.

Injecting drug use: sharing and re-using injecting equipment

The major mode of transmission of hepatitis C in Australia is through unsafe drug injecting practices, in particular the sharing and reusing of injecting equipment. Around 80 per cent of prevalent infections in Australia are attributed to injecting drug use.¹ Transmission occurs through the sharing of needles and syringes, and may also occur through the sharing of injecting equipment such as spoons and tourniquets.

Incarceration

Correctional Centres and Juvenile Justice Centres are recognised as a high-risk environment for the transmission of hepatitis C. Hepatitis C prevalence is 40 per cent among male inmates and 64 per cent among female inmates.⁷ Among young people in custody research has found hepatitis C prevalence of 8 per cent among males and 18 per cent among females.²

A large proportion of the prison population has a history of injecting drug use (53 per cent of male inmates and 73 per cent of female inmates). A significant proportion of inmates and detainees continue to inject drugs while incarcerated. The unavailability of clean injecting equipment and sterile tattooing equipment leads to high risk behaviour such as sharing needles/syringes and using home made tattoo guns without proper means of sterilisation. Barbering using unclean equipment is also a risk. Prisons can also be violent environments, which increases risk of exposure to infected blood.

Skin penetration practices (tattooing, body piercing)

Skin penetration practices with unsterile equipment, in particular tattooing and body piercing, but also acupuncture are potentially high risk. Because of the lack of knowledge about the risk of transmission, it is difficult to estimate how many people may be infected this way. Skin penetration guidelines and resources have been developed in NSW to minimise the risk of infection through unsterile equipment.

There may be a low risk of transmission from other procedures, such as at hairdressers or beauty salons, where instruments, such as cutthroat razors, barbers shears, scissors, nail files, are not properly cleaned.

Unsterile medical procedures

The risk of contracting hepatitis C through medical procedures is low in Australia. A large number of people living in NSW may have contracted hepatitis C through medical procedures in countries overseas where there is high prevalence of hepatitis C such as in southern European countries, some Middle Eastern countries, and some Asian countries. There is some evidence of poorer awareness of hepatitis C among these communities in NSW.³

Unscreened blood transfusions and blood products

In 1990 an antibody test became available and screening for hepatitis C was introduced for blood donations and blood products. Since the introduction of screening, the risk of contracting hepatitis C by this means is considered to be minimal.

Occupational exposure in health care and other settings

Occupational exposure of health care workers has led to infection but the statistical risk is low. People working in other areas where there may be exposure via blood

splashes, such as correctional settings, may also be at risk. Standard infection control procedures should be adopted to minimise the risk of contracting hepatitis C through occupational exposure.

Vertical transmission

The risk of mother-to-child transmission is less than 3 per cent if the mother has chronic hepatitis C and detectable virus in the blood. Most infants born to hepatitis C positive mothers will not go on to become infected. Breastfeeding is not generally considered to add to the risk of transmission.

Household

The risk of transmission through normal household contact is minimal. The risks appear to be through sharing items such as toothbrushes and razors. These risks can be minimised by not sharing personal household items.

Sexual contact

The risk of contracting hepatitis C through sexual contact is very low. There is an increased risk during sexual activities which involve blood-to-blood contact. There is also some evidence that people with immune system related illnesses, such as HIV, may be at higher risk.⁴

2.3 Prevalence, incidence and notifications

Over the last decade hepatitis C has been the most commonly notified infectious disease in Australia. A mathematical model of the hepatitis C epidemic estimated that there were around 264,000 people were living with hepatitis C virus antibodies in Australia in 2005⁵ including 154,000 with chronic hepatitis C and stage 0/1 liver disease, 38,000 with stage 2/3 liver disease and 5,300 with hepatitis C related cirrhosis. A further 67,000 had cleared their infection.⁶

The estimated incidence rate in 2006 was 9,700 new infections in Australia. This is a considerable decrease on earlier estimates of incidence, with mathematical modelling published in 2002, which estimated an annual incidence of 16,000 new infections per year. It should be noted that estimates of incidence are highly uncertain. It is estimated that over 70 per cent of people with hepatitis C in Australia have been diagnosed.¹ The national projections project notes the higher prevalence among Indigenous Australians, people from high prevalence countries and people held in prison.

Hepatitis C prevalence and incidence estimates are limited by current surveillance systems. Population prevalence estimates are dependent on estimates of the number of people who inject drugs. Population-based prevalence data is scarce, and current testing methods are unable to distinguish between new and existing infections.

NSW accounts for around 40 per cent of notifications in Australia.⁶ Up to the end of 2005, approximately 93,400 people in NSW had been notified as carrying hepatitis C antibodies. Notifications in NSW reached a high of 8,688 in 2001, before falling to 4,452 in 2005.⁷ This represents a decrease of approximately 48 per cent. Significant falls in the number of needles/syringes distributed through the needle and syringe program and ambulance call out rates for drug overdose indicates a reduction in injecting drug use. It is expected that new estimates of incidence and prevalence will take into account such developments, given that injecting drug use is the major transmission mode of hepatitis C.

Measuring the outcome of infection is difficult. It is estimated that, at the end of 2005, in Australia there were about 5,300 people in Australia with hepatitis C related cirrhosis. Forty per cent (2,120) of these cases would be expected to be in NSW.

The large population of people with hepatitis C, together with estimates of continued high hepatitis C incidence and the often long latency of hepatitis C related disease, will produce an escalating health burden for at least the next two decades. The already increasing incidence of hepatocellular carcinoma is thought to be related to the expanding hepatitis C epidemic, and cirrhosis due to chronic hepatitis C infection is already the most common underlying reason for liver transplantation.

The number of people living with hepatitis C related cirrhosis, incident cases of liver failure and hepatocellular carcinoma, and cumulative numbers of hepatitis C related deaths are all projected to at least treble by 2020.¹

2.4 Personal costs

Chronic hepatitis C related illness can affect many aspects of a person's life including their employment, family and social relationships, and participation in the community. Being diagnosed with or having hepatitis C can also cause anxiety and depression, and lead to uncertainty, fear and helplessness. The *National Hepatitis C Testing Policy* contains guidelines on appropriate testing procedures, including adequate pre- and post-test counselling, which are intended to alleviate the negative impact of a positive diagnosis.

Hepatitis C can affect people from different sub-populations and cultural backgrounds differently. Disapproval of injecting drug use, cultural factors such as poor understanding of and fears about confidentiality, and shame and language barriers can impact significantly on a person's access to services. In turn this can impact on how a person copes with their illness.

Antiviral therapy is expensive, although the majority of people would be able to access subsidised antiviral therapy under the Pharmaceutical Benefits Scheme. Being on treatment can also have a negative impact on a person. Many people on antiviral therapy experience side effects such as depression and mood swings, although most people are able to manage their side effects and few people cease treatment due to side effects. Many people also choose to access alternative treatments or complementary therapies, which are not subsidised by the government and which can be expensive.

It should be noted that the *NSW Anti-Discrimination Act* covers discrimination against people with hepatitis C, on the grounds of disability. Section eight of this Strategy focuses on discrimination.

2.5 Economic costs

The exact health costs associated with hepatitis C are unknown. For 1996/97, conservatively calculated direct costs nationally of the disease were \$75 million. Indirect costs, including loss of production resulting from premature death or absenteeism, were calculated at \$32.5 million.⁸

It was estimated that further costs of \$46 million would occur over 50 years for every 1,000 new infections. This included \$13 million in direct costs and over \$33 million in indirect costs, undiscounted and based on treatment protocols at that time.

A study of Australian needle and syringe programs in 2002 examined their economic effectiveness, including their effectiveness in preventing hepatitis C transmission. From the time of the introduction of needle and syringe programs in 1988 until 2000, it is estimated that they have prevented 21,000 hepatitis C infections. It was estimated that total treatment costs avoided over the lifetime of cases was \$783 million.⁹

Since its introduction in 2000, there are also significant costs involved in screening of blood donations using nucleic acid testing technology.

Prevention and education

Reducing the number of new hepatitis C infections is the major priority in controlling hepatitis C. The significant reduction in the reported prevalence of injecting drug use and the decline in hepatitis C notifications in recent years notwithstanding, the continuing high incidence rate presents a major challenge that demands an imaginative and multi-faceted response.

Most importantly, hepatitis C prevention services must target individuals and populations most at risk of hepatitis C infection. People who inject drugs, including people new to injecting or at risk of initiating injecting drug use, are at greatest risk.

Other groups, in particular people with medically acquired hepatitis C and people from CALD backgrounds, may be unaware that they may have been at risk and, subsequently, not know their hepatitis C status. These groups require education about hepatitis C and its risk factors. Improving prevention and education efforts within correctional, health care and other settings is also a priority.

There is ample evidence that needle and syringe programs are effective in reducing the incidence of hepatitis C and represent an effective financial investment. The NSW Needle and Syringe Program remains the key strategy to reduce hepatitis C incidence and other harm associated with injecting drug use. Major challenges facing the program are ensuring its sustainability, ensuring it meets the needs of people who inject drugs and improving accessibility for Aboriginal people.

Because of the complexity of issues facing many people at risk of hepatitis C, effective hepatitis C prevention and education interventions require better linkages between hepatitis C services, alcohol and other drug services, mental health services, youth services, Aboriginal services and multicultural services.

This Strategy also recognises the importance of ensuring the general community in NSW is well informed about hepatitis C to combat unfounded fears of transmission, which, in turn, can reduce hepatitis C stigma and discrimination.

3.1 People who inject drugs (including people at risk of initiating injecting drug use)

Hepatitis C prevalence is highest among people who inject drugs. Seventy-one per cent of NSW respondents in the most recent Australian Needle and Syringe Program Survey were hepatitis C antibody positive.¹⁰ Moreover, nine out of ten new hepatitis C infections are estimated to be due to injecting drug use.

It is difficult to reliably estimate the number people who inject drugs on a regular or occasional basis in NSW. In a recent representative sample of Australian adults, 3 per cent of respondents reported they had ever injected drugs, with men significantly more likely to report past or current drug injecting.¹¹

Injecting drug use is illicit. Because of that, and widespread lack of knowledge about hepatitis C and other blood-borne viruses, injecting drug use continues to be highly stigmatised, and people who inject drugs continue to face high levels of discrimination and marginalisation. As a consequence, it can be difficult to engage people who inject drugs in hepatitis C prevention, education and health promotion initiatives.

Injecting drug use must be understood as both individual behaviour and social practice. Drug use practices are influenced by individual, group, sub-cultural, environmental, political, legal, historical and structural dynamics, which must be taken into account in the design and delivery of hepatitis C prevention interventions. A focus on risk factors, individual responsibility and individual behaviour change that ignores risk contexts and settings limits the potential impact of hepatitis C prevention efforts.

Reducing the number of new hepatitis C infections requires prevention initiatives that effectively target people who inject drugs, both those with and without hepatitis C, as well as people at risk of commencing injecting drugs.

Preventing hepatitis C transmission among people who inject drugs requires a multi-faceted approach

that acknowledges the complexity of settings and contexts that shape risk-taking behaviours and practices, and includes a range of strategies and interventions aimed at:

- Developing social, cultural and legal environments that enable and support people who inject drugs to adopt safer injecting practices
- Providing people who inject drugs with the information and means to adopt safer injecting practices
- Promoting peer education on safer drug use and injecting
- Reducing the prevalence of injecting through strategies aimed at reducing or delaying the uptake of injecting
- Promoting alternative routes of drug administration
- Promoting access to drug education and drug treatment programs.

Ensuring that people who inject drugs have access to sterile injecting equipment and appropriate education is essential to reducing the incidence of hepatitis C. The NSW Needle and Syringe Program remains the key strategy to reduce hepatitis C incidence. Ensuring improved access to the NSW Needle and Syringe Program by Aboriginal people who inject drugs is a priority.

A substantial number of people who inject drugs do not access the NSW Needle and Syringe Program and other harm reduction services. Their reluctance is often linked to the stigma associated with drug use. They commonly access injecting equipment from pharmacies or through informal networks such as partners and friends. A range of strategies to reach people who inject drugs need to be considered. In some cases peer education initiatives can provide a significant contribution by providing education to people who are unable or unwilling to access programs or services. Outreach strategies can also be effective at reaching people who inject drugs who do not access or infrequently access the NSW Needle and Syringe Program.

Longer term strategies aimed at reducing the prevalence of drug use and injecting drug use through targeted drug education and treatment for drug dependency can contribute significantly to efforts to reduce hepatitis C transmission. Further initiatives to explore strategies that delay or prevent initiation into injecting drug use, or which shift people from injecting to non-injecting methods of drug administration should be encouraged.

People who inject drugs are not a homogenous group. Various subpopulations can be identified, each with particular challenges for hepatitis C prevention. Important sub-populations of people who inject drugs and have additional prevention and education needs include Aboriginal people, the young or inexperienced, people who live in rural areas, homeless people, CALD people, inmates and detainees. These needs are associated with:

- Lack of knowledge about safe injecting and blood-borne viruses
- Cultural and language barriers to accessing harm reduction and other health services
- Fear of being identified as a person who injects drugs within a small community
- Additional pretexts for potential discrimination.

Hepatitis C services also need to consider that some people who inject drugs may have co-morbidities such as HIV or mental health problems, and that links with HIV and mental health services might be required.

People who inject drugs in rural and remote areas may not have appropriate programs and services available within their local area, requiring them to travel long distances. Where services are available concerns regarding privacy and confidentiality might inhibit their willingness to access such services.

Community acceptance of harm reduction strategies, such as the NSW Needle and Syringe Program, remains important. Support could further be enhanced by targeted initiatives to improve knowledge and understanding of hepatitis C and harm reduction strategies. Inappropriately discarded needles and syringes are of great concern to the community. In response NSW Health established the Needle Clean Up Hotline and the Community Sharps Project.

3.2 Correctional settings

The rate of hepatitis C infection in both adult and juvenile inmates and detainees is high. The 2001 Inmate Survey reported that 40 per cent of men and 64 per cent of women in NSW Correctional Centres were hepatitis C positive.¹² The 2003 NSW Young People in Custody Health Survey reported a hepatitis C prevalence of 8 per cent among males and 18 per cent among female detainees.²

A substantial proportion of inmates and detainees of have a history of injecting and other drug use. Seventy-four per cent of adult female inmates and 67 per cent of male inmates in NSW Correctional Centres reported using illicit drugs regularly in the twelve months before incarceration.¹² Nineteen per cent of juvenile detainees reported injecting drugs in the twelve months prior to incarceration.²

The high prevalence of hepatitis C combined with the high incidence of violent behaviour in custodial settings make prison an environment in which a range of behaviours put inmates at increased risk of hepatitis C infection including:

- Sharing and re-using injecting equipment
- Unsterile tattooing, body piercing and other skin penetration practices
- Blood exposure resulting from assaults and sports injuries
- Sharing of personal grooming equipment such as razors
- Sex where blood is present.

The prevention and education needs of Aboriginal inmates and detainees need to be specifically addressed, given their over-representation within NSW Correctional Centres and Juvenile Justice Centres.

NSW Correctional Centres and Juvenile Justice Centres are not drug free. A small but significant number of inmates and detainees injects drugs while incarcerated. As they do not have access to sterile injecting equipment, the risks of transmitting hepatitis C and other blood-borne viruses are high.

Justice Health has primary responsibility for responding to hepatitis C in correctional settings. In 2003, Justice Health released *Hepatitis C Strategic Directions 2003–2006*. It acknowledges that the challenges of hepatitis C in Correctional Centres and Juvenile Justice Centres require a coordinated approach to hepatitis C prevention and management, which, in turn, requires improved collaboration between Justice Health, the NSW Department of Corrective Services and the NSW Department of Juvenile Justice.

For many inmates and detainees, the custodial setting provides an opportunity for health promotion and protection interventions not accessed when in the community. People in custody need information about hepatitis C transmission, treatment and management to enable them to assess risk and

to help them make informed decisions about protection, testing and counselling.

Currently inmates and detainees in NSW have access to the following hepatitis C prevention services:

- Hepatitis C screening
- Hepatitis C information and education
- Detergent solution for cleaning injecting equipment
- Hepatitis A and B vaccination
- Drug treatment.

The relatively high prevalence of hepatitis C and other blood-borne infections in young people in Juvenile Justice Centres, in combination with the high prevalence of injecting drug use and a range of other health issues, highlights the need for hepatitis C prevention with young people at high risk of infection. Effective prevention strategies for the diversity of young people in custody must take account of their needs, and assist them in developing and strengthening the skills that enable these young people to make informed choices regarding drug use and adopt practices that reduce their risk of hepatitis C infection.

Access to drug treatment, such as methadone maintenance therapy and Buprenorphine, in some settings assists in preventing hepatitis C infection by reducing the number of inmates and detainees injecting drugs. Inmates and detainees do not have the same access to harm reduction strategies that are available to the community. Current NSW Government policy does not allow for the distribution of sterile injecting equipment in NSW Correctional Centres and Juvenile Justice Centres.

In 2002, the Australian National Council on Drugs recommended that each jurisdictional department responsible for the management of prisons and juvenile detention centres, in consultation with staff, health authorities and relevant community-based organisations, develop occupationally safe and culturally appropriate policies, protocols and procedures regarding the introduction of trial needle and syringe programs within at least one of its prisons and juvenile detention centres.

Needle and syringe distribution or exchange programs in correctional settings have been established and evaluated in several countries, including Spain, Switzerland, Germany, Moldova, Kyrgyzstan and Belarus. Reviews of existing prison-based needle exchange programs have been favourable, indicating that these programs were associated with stable or decreased

levels of drug use, substantial declines in syringe sharing as well as no new cases of HIV or hepatitis C infection. These programs were also found not to undermine efforts to reduce drug use. Staff attitudes towards these programs were found to be generally positive.

Drug diversion schemes

Illicit drug use is a major factor in people coming into contact with the criminal justice system. The imposition of custodial and non-custodial sentences can act as a deterrent to illicit drug use in some instances. However, for those people who are drug dependent, sentencing in itself does not resolve the underlying issue.

Following the meeting of the Council of Australian Governments in April 1999 a series of pilot projects were established in NSW designed to divert drug offenders from the criminal justice system. These pilot projects are funded by the Australian Government under a specific funding agreement.

The Magistrates Early Referral into Treatment Project is for people charged with any drug or drug related offence (subject to certain conditions). The project allows the person charged an opportunity to voluntarily enter a treatment program as a bail condition set by the Magistrate, prior to a plea being entered.

Following much debate concerning illicit drug use, its impact on the community and its relationship to crime, NSW established a Drug Court at Parramatta on 8 February 1999 to help offenders overcome their drug dependence and end their associated criminal behaviour through court enforced and supervised treatment programs. Youth Drug Courts were also established to assist young offenders.

This Strategy supports the various drug diversion schemes, acknowledging that hepatitis C prevention benefits greatly from these and other efforts to reduce the numbers of incarcerated people who inject drugs.

3.3 Occupational exposure

Health care workers, corrections officers and workers in several other settings are at risk of occupational exposure to needlestick injuries and blood splashes. Development and implementation of policies that promote standard infection control precautions is required.

Standard infection control precautions should be implemented for all procedures when there is a risk of contact with blood or other body substances. They

are the minimum strategy in preventing occupational exposures to hepatitis C. Standard infection control precautions require health care workers to assume that blood and other body substances to be sources of infection. Standard infection control precautions include hand hygiene, wearing appropriate personal protection equipment, and the safe handling and disposal of equipment soiled with blood and body substances.

Under occupational health and safety legislation, employers are required to provide the information, instruction, training and supervision necessary to ensure the health and safety of employees at work.

The NSW Department of Health Policy Directive *Infection Control Policy* (PD2005_247) provides the overall infection control framework for Area Health Services and health care facilities. Specific additional guidelines exist for a range of specific settings, including:

- *Waste Management Guidelines for Health Care Facilities* (PD2005_132)
- *HIV, Hepatitis B or Hepatitis C – Health Care Workers Infected* (PD2005_162)
- *Infection Control Management of Reportable Incidents* (PD2005_203)
- *Occupational Assessment, Screening and Vaccination Against Specified Infectious Diseases* (PD2007_006)
- *Incident – Effective Incident Response Framework for Prevention and Management in the Health Workplace* (PD2005_234)
- *Infection Control Guidelines for Oral Health Care Settings* (GL2005_132)
- *HIV, Hepatitis B and Hepatitis C – Management of Health Care Workers Potentially Exposed* (PD2005_311).

Reducing the risk of hepatitis C infection among health care and other workers requires:

- Improving access to training and education in infection control
- Supporting adherence to infection control guidelines and protocols
- Improving monitoring of infection control policy implementation.

Clients and staff in the skin penetration industry

The risk of occupational exposure may be elevated in clients and workers in the skin penetration industry. Although prevalence rates are estimated to be low

among people who have had tattoos and body piercings, the potential for hepatitis C to be transmitted through such procedures is significant considering that many practitioners do not appear to understand and adhere to the infection control guidelines for the skin penetration industry.

There exist a range of guidelines and codes of best practice on skin penetration, which require tattooists and body piercers to apply appropriate infection control procedures to minimise the risk of blood-borne virus transmission. These guidelines include the *Skin Penetration Guidelines* and *Skin Penetration Code of Best Practice*. There is a need to improve knowledge of and adherence to these guidelines.

Local councils have an important role in monitoring skin penetration practices' compliance with the various guidelines.

3.4 Other populations and settings

Low knowledge of hepatitis C, in particular about how it is transmitted, is at the root of current stigmatisation and marginalisation of people with, or assumed to have, hepatitis C. Combating this ignorance requires promoting blood awareness in the community by helping people to understand the potential risks of blood in any situation and providing them with basic infection control information to protect themselves against infection.

Schools could contribute significantly to the prevention of hepatitis C and other blood-borne viruses through implementing the existing curriculum on blood awareness. Educating young people to be aware of blood alerts them to the potential risk of blood in any situation and enables them to adopt practices to avoid transmission of blood-borne viruses.

SECTION 4

Testing

Testing is the primary tool in diagnosing infection and assessing the prognosis for people with chronic hepatitis C. The manner of informing people that they have hepatitis C largely shapes their understanding of their infection. Testing needs to be undertaken with the informed consent of the patient. Adequate pre- and post-test counselling should be the standard to prevent or reduce uncertainty, fear and helplessness associated with being diagnosed with hepatitis C. The *National Hepatitis C Testing Policy* provides comprehensive guidelines, including population groups to be targeted for testing.

Testing for hepatitis C infection is available through a range of private and public sector outlets, including general practice, drug and alcohol services, sexual health services and Aboriginal Community Controlled Health Services.

Specific priority populations have differing needs in relation to the promotion of and access to hepatitis C testing. For some populations – such as migrants from countries of high hepatitis C prevalence – awareness of potential hepatitis C infection may be low and testing may require more active and targeted promotion. For other populations, promotion of testing may need to include a greater emphasis on the benefits of knowing one's hepatitis C status and management options.

Treatment

It is not always possible to draw a clear line between clinical treatment and non-clinical care. It is important to recognise that the majority of people with hepatitis C will not be receiving clinical treatment at any one time. Even so, they do have significant health service needs, in particular with regard to testing, monitoring, counselling and information. Similarly, people receiving treatment, be it antiviral therapy or treatment for advanced liver disease, have care and support needs.

Information and education on antiviral therapy and treatment support services need to be culturally appropriate and relevant for the diversity of people with hepatitis C.

When people who inject drugs, currently or in the past, seek hepatitis C treatment, care or support services they may face discrimination associated with their drug use. People with medically acquired hepatitis C may also be subjected to discrimination associated with suspicion of past or current drug use. Aboriginal and CALD people with hepatitis C may have difficulty finding information and clinical support that is culturally and linguistically appropriate. This Strategy is committed to promoting equitable and appropriate access to treatment services to the diversity of people with hepatitis C.

Antiviral therapy

Antiviral therapy outcomes for hepatitis C have improved significantly. Although side effects remain, the benefits potentially outweigh the costs for many people eligible for antiviral therapy. With improvements in the efficacy of drug treatments, it is likely that there will be an increase in the number of people on or seeking antiviral therapy.

Currently, only a small proportion of people with chronic hepatitis C access antiviral therapy. Access to antiviral therapy is constrained by:

- Eligibility criteria
- Lack of knowledge of treatment options and outcomes among people with hepatitis C
- Lack of knowledge of treatment options and outcomes among health care providers
- Side effects of antiviral therapy
- Geographic and physical location of treatment services (liver clinics)
- Limited capacity of existing hepatitis C services
- Psychosocial issues
- Fear associated with liver biopsy
- Cultural and linguistic barriers
- Incarceration
- Experiences with discrimination in health services.

This Strategy aims to reduce barriers to antiviral therapy.

Given the potentially significant side-effects of antiviral therapy, it is important that those contemplating antiviral therapy can make informed decisions through the provision of adequate pre-treatment counselling. Once on antiviral therapy, people need to be carefully managed for side-effects and to complete treatment.

Hepatitis C antiviral therapy for the majority of people is largely provided on an ambulatory basis. Inpatient admissions are for people undergoing liver biopsies to determine whether antiviral therapy is appropriate, and for those people with complications arising from their hepatitis C infection or with advanced liver disease. Since April 2006, liver biopsies have been removed as a standard requirement for all people seeking to access antiviral therapy and are only required in specific clinical circumstances.

Management of liver disease

Monitoring of cirrhosis development and surveillance for early diagnosis of primary liver cancer in patients with persistent infection requires an ongoing collaboration between the patient, their GP and specialists.

Treatment also includes management of more advanced liver disease and all its complications. This requires a multidisciplinary approach involving a wide range of specialist services, including gastroenterology, hepatology,

infectious diseases, specialist nurses, dieticians, endocrinology, radiology, liver transplantation, GPs and others. The care is both inpatient and ambulatory.

Service providers

A range of health service providers is involved in delivering clinical treatment and non-clinical care and support services to people with hepatitis C.

General practitioners

GPs are the primary point of diagnosis for people with hepatitis C, and should be equipped with adequate knowledge and capacity to provide pre- and post-test counselling. GPs are increasingly seen as the primary carer in the management of hepatitis C.

The aim should be for all GPs to provide a standard level of care in relation to hepatitis C. Those GPs with a special interest in hepatitis C should have the opportunity to participate in shared care arrangements with private and hospital-based specialists.

In recent years, primary care providers have been targeted to enhance their capacity to provide services to people with hepatitis C, including testing and more recently, treatment. Through the NSW Department of Health's Hepatitis C s100 Community Prescribing Pilot, 122 GPs across NSW have received training and education in hepatitis C clinical management from the Australasian Society for HIV Medicine. Eighty-two of these GPs have been accredited to prescribe s100 drugs for hepatitis C antiviral therapy.

GPs should also be supported in providing shared care, including lifestyle interventions and cancer screening.

Specialists

Specialists based in hospitals lead the provision of antiviral therapy to people with chronic hepatitis C. They include gastroenterologists, hepatologists and infectious disease physicians from the public and private sector. Specialists play an important role in supporting general practitioners who have been accredited to prescribe s100 drugs.

Nurses

Nurses, in particular clinical nurse consultants and clinical nurse specialists, are responsible for much of the day-to-day treatment needs of people with hepatitis C. They can be and often are the vital link between patient and specialists. They are also likely to have a greater link to GPs providing care for people with hepatitis C.

In view of the growing demand for complex clinical services, the need for introducing nurse practitioners in hepatitis C or hepatology should be investigated.

Aboriginal Community Controlled Health Services

Aboriginal Community Controlled Health Services are the best practice model for the delivery of comprehensive primary health care to Aboriginal communities. Aboriginal Community Controlled Health Services should be supported to provide hepatitis C treatment, care and support services to Aboriginal people with or at risk of hepatitis C.

Allied health

A wide range of allied health service providers are involved in delivering health services to people with hepatitis C. Allied health includes dieticians, social workers, clinical psychologists and counsellors. They have an important role in supporting people on antiviral therapy in managing treatment side effects. They also play an important role in supporting the health of people with chronic hepatitis C not receiving clinical treatment.

Community-based organisations

Both the Hepatitis C Council of NSW and NSW Users and AIDS Association have important roles in providing information, peer education and support to both people with hepatitis C in treatment and people with hepatitis C not receiving clinical treatment.

Justice Health

The provision of clinical care and treatment services to inmates and detainees of NSW Correctional Centres and Juvenile Justice Centres is outlined in and guided by Justice Health's Hepatitis C Strategic Directions 2003-2006, as well as a complementary set of Hepatitis Management Guidelines and Information Manual. The strategic directions document articulates a model of service delivery that aims to:

- Provide high quality standardised hepatitis C prevention and care services across correctional centres;
- Improve continuity of care across Justice Health clinical programs and between Justice Health services and services in the community
- Improve access to services to meet the health needs of inmates within the available resources
- Improve integration between clinical care for inmates with hepatitis C and hepatitis prevention efforts.

It also recognises some of the complexities of providing clinical services to inmates and detainees, including the need to frequently move an inmate to a correctional centre where a clinic is located, as well as the pressure on nursing staff to meet demand for treatment.

Health maintenance, care and support

People with hepatitis C have a range of health maintenance, care and support needs. These may include health monitoring, support to access to treatment, counselling, psychosocial support, information and health maintenance support.

Physical, psychological and environmental issues and contexts have an impact on the health, well-being and quality of life of people with hepatitis C. Various physical conditions can impact on the health and well-being of people with hepatitis C, including co-infection with HIV, hepatitis A or hepatitis B, and co-morbidities (such as diabetes and obesity). These can exacerbate symptoms or lead to more severe prognosis.

The treatment of hepatitis C infection and associated liver disease alone is insufficient to ensure health and well-being. Symptoms of hepatitis C, such as fatigue, nausea, headaches, as well as treatment side-effects, need to be managed. Other aspects affecting the health and well-being of people with hepatitis C fall outside the scope of specialist hepatitis C services.

The majority of people with hepatitis C do not receive antiviral therapy or other specialist hepatitis C clinical care. However, they do require periodic assessment of their hepatitis C status, information on nutrition, alcohol and exercise, as well as the benefits of hepatitis A and hepatitis B vaccination. Some may also require psychosocial support and counselling.

A wide range of services and organisations are involved in supporting people with chronic hepatitis C to manage and maintain their health, well-being and quality of life. These services include drug and alcohol services, mental health services, and community organisations.

These services and organisations may assist people with hepatitis C to deal with issues such as:

- The stress and anxiety associated with having a chronic illness
- Pre-existing psychiatric conditions, such as depression or other mental health problems
- Excessive alcohol intake, which can accelerate fibrotic progression in chronic hepatitis C.¹³

Complementary health is a heterogeneous collection of therapeutic substances and techniques based on theory and explanations that are not consistent with the western clinical model of medicine. It includes traditional Chinese medicine, naturopathy and herbal medicine. Many people with hepatitis C access some form of complementary health to relieve symptoms and improve their general quality of life. This Strategy supports efforts to ensure safety in complementary health practices.

Support services should be accessible for the diversity of people with hepatitis C, including:

- People who inject drugs or used to, some of whom may be on antiviral therapy
- Adult and juvenile inmates and detainees – in custody and on release
- CALD people
- Aboriginal people with hepatitis C
- People with medically acquired hepatitis C
- People who are co-infected with HIV and/or hepatitis B
- People with mental health problems
- Personal networks of people with hepatitis C, comprising partners, relatives, friends and colleagues.

Infrastructure and support

Surveillance and research

Knowledge about hepatitis C underpins the ability to respond effectively to the disease. There remain gaps in knowledge about incidence and prevalence, natural history, prevention, treatment, costs and long-term outcomes of hepatitis C. Surveillance and research are fundamental to improving knowledge, and to providing an evidence base that informs policy, program development, clinical treatments and therapies, and service design and delivery.

Effective surveillance is essential in efforts to control the spread of hepatitis C. However, precise monitoring and surveillance of the prevalence and incidence of hepatitis C is inherently difficult for a number of reasons:

- Acute infection is mostly asymptomatic
- A significant proportion of people with hepatitis C were infected prior to identification of the virus – they may not be aware that they ever were at risk of infection and their infection remains undetected while asymptomatic
- Current tests cannot distinguish between new and old infections
- Tests that distinguish active infection from latent are expensive and availability is limited
- There are variations in the accuracy and completeness of data relating to priority populations, in particular Aboriginal people and people from culturally and linguistically diverse backgrounds
- The major route of transmission, injecting drug use, is illicit.

Research is generally the responsibility of the Australian Government and pharmaceutical companies. NSW Health supports research by providing a significant proportion of the infrastructure and personnel, and at times funding, to conduct surveillance activities and social research. Improving the available research and surveillance relating to priority populations is a priority within this current Strategy. In particular, increasing the completeness and accuracy of information relating to

Aboriginality and epidemiology among people from culturally and linguistically diverse backgrounds is a priority, as is expanding the social and behavioural research available to inform program and service delivery with these populations.

Clinical and virological research is of great importance in understanding the nature of the virus, and the potential to develop a prophylactic or treatment. Clinical trials are necessary to determine the effectiveness and safety of any vaccines or treatments.

Social research improves understanding of risk-taking behaviours and contexts, the needs and experiences of people with or at risk of hepatitis C, and efficacy of hepatitis C prevention and education. Social research provides crucial information for developing and delivering appropriate and targeted prevention and education programs.

Workforce development

A skilled and knowledgeable workforce is crucial for providing effective prevention and health promotion programs and quality treatment, care and support services.

This Strategy is committed to supporting workers in the provision of equitable and accessible services and programs that are culturally appropriate for the diversity of people with or at risk of hepatitis C.

All health care workers should be made aware of hepatitis C, in particular about infection risk and how to prevent infection. Awareness and knowledge of hepatitis C and other blood-borne viruses should be part of pre-entry education in all health professions.

Currently, various organisations provide a broad range of both formal and informal learning opportunities for health care workers in relation to hepatitis C, including:

- NSW Health Workforce Development Program in Hepatitis, HIV and Sexual Health which provides a range of workforce and management development strategies and projects for workers across NSW.

- Australasian Society in HIV Medicine which provides hepatitis C training and accreditation for community-based medical practitioners through the Hepatitis C Prescriber Accreditation Program.
- Hepatitis C Council of NSW which provides support, education and workforce development to health service providers working with people with or at risk of hepatitis C.
- Aboriginal Health and Medical Research Council of NSW which provides support, education and workforce development for Aboriginal Sexual Health Workers and other Aboriginal workers.

The diverse training, education and support needs of health care workers providing services to people with or at risk of hepatitis C needs to be recognised, and interventions need to be implemented to meet those needs.

A key priority of this Strategy is increased collaboration between specialist clinics and primary care providers, such as GPs, in providing shared care and treatment services.

Another priority of this Strategy is engaging the NSW Needle and Syringe Program, drug and alcohol, sexual health and community health services in hepatitis C service delivery. The primary rationale for involving these services is that they are often the first or only contact people who inject drugs have with health services. Equipping workers in these services to deal effectively with these clients should be a priority.

There is no single model for providing workforce development to health care workers, and the challenges posed by hepatitis C require a multi-faceted approach to delivering programs. Priority populations to be considered in workforce development include:

- Health care workers, including specialists, nurses, GPs, alcohol and other drug workers, NSW Needle and Syringe Program staff, sexual health and community and allied health workers
- Aboriginal Sexual Health Workers and Aboriginal health workers
- Staff in Correctional Centres and Juvenile Justice Centres
- Staff in relevant community based organisations.

Partnerships

Partnerships between the government, health sector, justice sector, research sector and community organisations are recognised as essential in responding effectively to public health concerns, and are a key feature of this Strategy.

Key stakeholders include:

- People with or at risk of hepatitis C and those representing them
- Specialist medical officers such as gastroenterologists, hepatologists and infectious diseases physicians
- Primary care providers such as GPs, nurses, drug and alcohol workers, NSW Needle and Syringe Program workers and sexual health workers
- Community, advocacy and support groups
- Aboriginal Community Controlled Health Services
- Services and programs working with CALD communities
- Allied health workers such as dietitians, clinical psychologists and social workers
- Professional organisations
- NSW Health, including Area Health Services and Justice Health
- Medical, scientific and social research bodies
- Education and workforce development institutions and organisations
- Peak organisations
- Local councils.

NSW Health

The health system in NSW has a devolved structure. The role of the NSW Department of Health is to set the broad parameters in matters of policy, planning and finance, while the provision of hospital and other health services is primarily a responsibility of Area Health Services and Justice Health. Areas enjoy a considerable degree of autonomy in the performance of their service provision and operational functions. The exercise of those powers occurs within a system of performance

standards and financial accountabilities that are developed, monitored and overseen by the Department.

The NSW Aboriginal Health Partnership between the Aboriginal Health and Medical Research Council of NSW and NSW Health assists in guiding appropriate responses to Aboriginal health issues in NSW. The Partnership seeks to improve health outcomes for Aboriginal people through, primarily, advising the Minister for Health on Aboriginal health policy, strategic planning, and broad resource allocation matters; ensuring that Aboriginal health remains a high priority in the health system; and obtaining resources to advance Aboriginal health.

Health workers

A diverse and heterogeneous range of health care workers is involved in providing services to people with hepatitis C from specialists through to primary care and allied health workers. This Strategy will seek to enhance the capacity of primary care health workers such as general practitioners, drug and alcohol workers, Aboriginal health workers and sexual health workers to provide services to people with or at risk of hepatitis C. Much of this will require the support of specialist clinics in providing expertise.

Community, advocacy and support groups

NSW Health funds a number of government and non-government community, advocacy and support groups to represent and provide services to people with or at risk of hepatitis C. These groups play an essential role in assisting the government to formulate its response to hepatitis C and are partners in the policy and decision making process.

Local government and local communities

Engaging local councils and local communities is essential for prevention programs to operate successfully. Local councils are responsible for approving building and development applications for services such as needle and syringe outlets and methadone clinics. Fostering a good working relationship with local councils is essential

in maintaining the success of drug and alcohol and NSW Needle and Syringe Program. It is also important for the community to better understand the importance of public health initiatives, which benefit not only the users of a service, but also the general community.

Government departments

Various government departments, in addition to health, are involved in providing services to people with or at risk of hepatitis C.

The NSW Department of Corrective Services and the NSW Department of Juvenile Justice are responsible for the safe custody of inmates and detainees of Correctional Centres and Juvenile Justice Centres. They have a duty of care to prevent the spread of hepatitis C and other infections among inmates and detainees.

Engaging the NSW Department of Education and Training is essential for school-based education programs on blood-borne infections and blood awareness.

SECTION 9

Discrimination

People with or at risk of hepatitis C should be treated with dignity and respect.

The 2001 Anti-Discrimination Board inquiry into hepatitis C related discrimination found discrimination to be common and widespread, in particular in health care settings.

Hepatitis C related discrimination remains a challenge. In its most overt form, people with or at risk of hepatitis C are refused health services on the basis of their hepatitis C status and/or past, current or assumed drug use. In its more covert form, people with or at risk of hepatitis C are made to feel that they have less entitlement to quality health care.

Prevailing negative community attitudes towards drug use translate into negative attitudes towards both people who inject drugs and people with hepatitis C. The common assumption that all people with hepatitis C are current or past drug users, is the main cause of the discrimination, stigmatisation and marginalisation of people with hepatitis C.

Discrimination, stigmatisation and marginalisation often have a profound impact on the lives of people with hepatitis C. Both actual discrimination and fear of discrimination and stigmatisation can cause people with hepatitis C to refrain from accessing hepatitis C and other health services. As such, it can affect their health, well-being and quality of life.

Discrimination, stigmatisation and marginalisation also impact on the lives of people at risk of hepatitis C. Discrimination and fear of discrimination are barriers to people at risk of hepatitis C accessing hepatitis C prevention, testing and other health services.

Greater effort should be made to address the stigma and discrimination faced by both Aboriginal people who inject drugs and CALD people who inject drugs, as they may further experience discrimination and stigma from within their own communities that may inhibit access to services and support for hepatitis C.

Ultimately, the health, financial, social and emotional consequences of hepatitis C related discrimination can be damaging for not only people with or at risk of hepatitis C, but also the community.

Hepatitis C related discrimination is unlawful on the grounds of disability. The enshrining of the principles of equality and non-discrimination in legislation provide a framework for reducing hepatitis C related discrimination.

It is likely that health care workers who are educated and trained adequately in dealing with hepatitis C (and other blood borne viruses) and drug use issues will treat people with or at risk of hepatitis C with the respect they are entitled to.

This Strategy is committed to reducing hepatitis C related discrimination through ensuring that health care workers and workers in other professions or settings in regular contact with people with or at risk of hepatitis C have access to education and training in hepatitis C and other blood-borne viruses and drug issues.

General community education and awareness programs will not only increase knowledge and understanding of hepatitis C, but also reduce hepatitis C related discrimination.

NSW Health role and responsibilities

10.1 Role and responsibilities

The NSW Health system, as it relates to hepatitis C, comprises the NSW Department of Health, Area Health Services, Justice Health and statewide services.

NSW Department of Health

The role of the NSW Department of Health is to:

- Develop strategies, policies and priorities for the prevention, control, care, treatment, support and monitoring and surveillance of hepatitis C across NSW
- Determine funding for Area Health Services and non-government organisations
- Support the Ministerial Advisory Committee on Hepatitis
- Monitor planning and service provision by Areas and non-government organisations
- Liaise with other government and non-government agencies
- Disseminate up to date information to Areas and other key stakeholders
- Liaise with the Australian Government, including through representation on the Inter-Governmental Committee on AIDS, Hepatitis C and Related Diseases.

Area Health Services

Each Area Health Service is responsible for the planning, coordination and funding of hepatitis C services and activities within its Area. The planning and delivery of services should be consistent with this Strategy and other relevant planning documents endorsed by the NSW Department of Health.

It is recognised that the organisation of services will differ from Area to Area depending on the prevalence of infection, differences in the infrastructure of health services and local need.

Area Health Services are responsible for delivering health services to people in NSW. They are responsible for:

- Providing care, treatment and support services to people with hepatitis C
- Implementing hepatitis C prevention, education and health promotion programs
- Conducting surveillance
- Developing networks and partnerships at a local level
- Determining funding priorities for hepatitis C at a local level.

Area Health Services will give priority to hepatitis C issues by developing plans and reporting back to the NSW Department of Health about initiatives they undertake.

Justice Health

Justice Health is responsible for providing clinical services to inmates and detainees at Correctional Centres and Juvenile Detention Centres in NSW, including:

- Providing testing and monitoring and surveillance of hepatitis C in prisons
- Providing care and treatment for inmates and detainees with chronic hepatitis C
- Providing methadone maintenance treatment for inmates and detainees with a heroin dependence problem and examining the provision of alternatives to methadone
- Managing the health of inmates and detainees.

The NSW Department of Corrective Services and the NSW Department of Juvenile Justice provide non-clinical services related to security and recidivism prevention to inmates and detainees.

Statewide services

Area Health Services auspice a number of statewide services that address hepatitis C related issues. The Multicultural HIV/AIDS and Hepatitis C Service undertakes and supports initiatives to address hepatitis

C in CALD communities. It also works to build the capacity of agencies to address hepatitis C amongst people from CALD backgrounds. The Workforce Development Program in Hepatitis, HIV and Sexual Health supports the development of the skills of health and community workers.

10.2 Advisory and coordination committees

Ministerial Advisory Committee on Hepatitis

The NSW Ministerial Advisory Committee on Hepatitis is the main advisory body in NSW dealing with hepatitis C related matters. The committee provides advice, raises issues for consideration, endorses policies and programs and recommends priorities in viral hepatitis. The committee was established in 2000, and its membership includes people from health, research, scientific and community backgrounds with expertise in viral hepatitis.

Drug and Alcohol Health Council

The NSW Drug and Alcohol Health Council is the overarching corporate governance body for the NSW Department of Health's Centre for Drug and Alcohol. It consists of representatives of drug and alcohol services, Centre for Drug and Alcohol, non-government organisations, and the Aboriginal Health and Medical Research Council of NSW. The Council advises the Centre for Drug and Alcohol on policy objectives and strategy directions.

Blood Borne Virus and Sexually Transmitted Infections Subcommittee

The Blood Borne Virus and Sexually Transmitted Infections Subcommittee of the Communicable Diseases Network Australia provides a forum for regular Australian Government and state/territory liaison on policy, finance, programs and activities to ensure continued cooperation and coordination. The committee includes state/territory health departments, the Australian Government Department of Health and Ageing and representatives from the affected communities.

Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis

The Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis is the key advisory body to the Australian Government Minister for Health and Ageing on policies and national strategies in relation to HIV/AIDS, indigenous sexual health, sexually transmissible infections and viral hepatitis. The committee is in turn advised by various sub-committees, including a hepatitis C sub-committee.

NSW Aboriginal Sexual Health Advisory Committee

The NSW Aboriginal Sexual Health Advisory Committee is chaired by the Aboriginal Health and Medical Research Council of NSW. It has responsibility for monitoring and overseeing Australian Government and NSW Government sexual health and blood-borne viruses strategies and implementation plans.

Monitoring and evaluation

The NSW Department of Health will be responsible for coordinating implementation of this Strategy.

A number of mechanisms will be developed to assist in the monitoring and evaluation of this Strategy.

The NSW Department of Health will undertake a review prior to the end of the term of this Strategy, in order to inform the further response to hepatitis C.

Oversight of strategy development and implementation

The NSW Ministerial Advisory Committee on Hepatitis will play a key role in overseeing the implementation of this Strategy. It will have the capacity to seek advice from NSW Health as to the status of strategy initiatives, and developments in hepatitis C during the term of this Strategy.

Development of an action plan

This Strategy will be complemented by an action plan aligned to key priorities.

Submission of annual funding plans from Areas

Areas are required to submit annual funding plans to the Department to ensure that funding accords with priorities set out in this and other strategic documents.

Submission of annual funding reports to Australian Government

NSW Health is required to submit annual funding reports to the Australian Government Department of Health and Ageing. The reports detail activities undertaken and address specific performance indicators agreed to between NSW and the Australian Government.

Evaluation reports for projects

Projects funded by NSW Health will be required to submit evaluation reports or project reports.

Surveillance reports

Regular surveillance reports are provided to the NSW Ministerial Advisory Committee on Hepatitis, with detailed information on hepatitis C notifications.

References

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