

Third National Hepatitis C Strategy 2010 - 2013

Contents

Contents	2
1. Background	3
1.1 Roles and responsibilities of parties to this strategy	3
1.2 Relationship to other strategies.....	4
1.3 Hepatitis C in Australia.....	4
2. Goal	6
3. Objectives and indicators	6
4. Guiding principles	7
5. Priority populations	8
5.1 People with hepatitis C	8
5.2 People who inject drugs.....	8
5.3 People in custodial settings.....	10
5.4 People from culturally and linguistically diverse backgrounds	11
5.5 People with hepatitis C with co-morbidities.....	11
6. Priority action areas	12
6.1 Prevention and education	12
6.2 A human rights framework for addressing stigma and discrimination.....	13
6.3 Testing and diagnosis of hepatitis C	13
6.4 Treatment, health and wellbeing	14
6.5 Models of care and clinical management.....	15
6.6 Health maintenance, care and support for people with chronic hepatitis C	16
7. Surveillance	17
8. Research	17
9. Workforce development	18
References	22

1. Background

This is the third National Hepatitis C Strategy to be adopted in Australia. It builds on two previous strategies which guided Australia's response to hepatitis C between 1999 and 2008. This hepatitis C strategy is one of a suite of five strategies that aim to reduce the transmission of sexually transmissible infections (STIs) and blood borne viruses (BBVs), and the morbidity, mortality and personal and social impacts they cause. This strategy's relationship to the other four strategies is detailed in section 1.2 below.

1.1 Roles and responsibilities of parties to this strategy

While governments are the formal parties to this document, a partnership approach has been central to the development of this strategy. This has included significant consultation with, and input from community organisations, researchers, clinicians and health sector workforce organisations. These organisations are represented on advisory committees detailed below that have provided valuable advice during the development process.

The priority actions identified in this strategy will be progressed through a continuation of this partnership between governments and the community sector, representing people with the infections and their communities, researchers, clinicians and health sector workforce organisations.

Leadership is provided by the Australian government which works through the Australian Health Ministers Council (AHMC) and its sub-committees to facilitate national policy formulation and coordination. The Blood Borne Virus and Sexually Transmissible Infections Sub-Committee (BBVSS) of the Australian Population Health Development Principal Committee (APHDPC) includes representatives of all governments as well as the community based organisations, and provides expert advice to health ministers through the APHDPC and the Australian Health Ministers Advisory Council (AHMAC). The Australian government also seeks advice through the Ministerial Advisory Committee for Blood Borne Viruses and Sexually Transmissible Infections (MACBBVS).

These groups will work in the context of funding arrangements for the health system, to reshape existing policies and programs or to extend them where possible. These funding arrangements are provided jointly by the Commonwealth and the States and Territories under the National Health Care Agreement, which is a Schedule to the Council of Australian Government's (COAG) Intergovernmental Agreement on Federal Financial Relations which came into effect on 1 January 2009. Related National Partnership Agreements provide the broad basis for funding reform in the Australian health system. Partnerships relevant to these strategies include the Indigenous Early Childhood Development Partnership and the National Essential Vaccines Partnership.

Australian governments fund community and professional organisations, program delivery organisations and research centres to engage with, and build the knowledge base in relation to communities affected by blood borne viruses and sexually transmissible infections so that effective responses can be put into place. The involvement of these organisations has assisted in developing the response to these health challenges.

1.2 Relationship to other strategies

This strategy is one of a suite of five strategies that aim to reduce the transmission of sexually transmissible infections (STIs) and blood borne viruses (BBVs) in Australia, and the morbidity, mortality and personal and social impacts they cause. The five strategies cover the period 2010-2013 and include:

- the Third National Hepatitis C Virus (HCV) Strategy (this strategy);
- the Sixth National HIV Strategy;
- the First National Hepatitis B Strategy;
- the Second National Sexually Transmissible Infections Strategy; and
- the Third National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy.

While the first four strategies focus on particular infections, the fifth strategy focuses on the combined health impact these infections have on Aboriginal and Torres Strait Islander peoples in Australia. Despite each of strategy's specific history and focus, together they share many features such as:

- some shared *Guiding principles* (chapter 4 in each strategy);
- some shared *Priority populations* (chapter 5 in each strategy);
- some shared or similar *Priority action areas* (chapter 6 in each strategy); and
- shared issues around *Surveillance, Research and Workforce development* (later chapters in each strategy).

The alignment of each stand-alone strategy's structure is designed to facilitate a co-ordinated effort across stakeholder groups with different focuses in recognition of common concerns.

1.3 Hepatitis C in Australia

Hepatitis C is a significant public health problem and one of the most commonly reported notified diseases in Australia. At the end of 2008, there were an estimated 284 000 people who had been exposed to hepatitis C with 212 000 estimated to have chronic hepatitis C.¹ An estimated 10 000 new infections occur annually, and this figure has declined since 2001.²

Hepatitis C is a blood borne virus (BBV), predominantly transmitted through sharing injecting equipment which accounts for approximately 90% of new infections and 80% of existing infections³. Transmission can also occur:

- through non-sterile tattooing and body piercing;
- through un-sterile medical or dental procedures particularly in countries of high hepatitis C prevalence;
- from mother to infant during delivery if the mother has detectable hepatitis C virus in her blood;
- in occupational settings through needlestick injuries and accidental exposures to infected blood or blood products in health care settings; and
- through transfusion of infected blood or blood products in Australia prior to 1990.

The prevalence of hepatitis C is disproportionately higher among people in custodial settings^{4,5} given the high prevalence of multiple risk factors including previous infection with hepatitis C and a high rate of imprisonment for drug-related crime; unsafe injecting drug use and unsterile tattooing and body piercing activities.

It is estimated 22 000 Indigenous Australians have been exposed to the hepatitis C virus, of which 16 000 live with chronic hepatitis C⁶. Aboriginal and Torres Strait Islander people constitute 2.4% of the Australian population yet make up 8.3% of the Australian population living with hepatitis C.

While hepatitis C is not classified as a sexually transmitted infection (STI), there is a risk of hepatitis C transmission if the blood of one person enters the bloodstream of another person during sexual intercourse. Men who have sex with men and who also have human immunodeficiency virus (HIV) infection have a higher proportion of hepatitis C transmission through sexual exposure compared to all people with hepatitis C infection.⁷

Around 75% of people exposed to hepatitis C develop chronic infection, defined as the presence of hepatitis C virus in the bloodstream for longer than six months. The remaining 25% will spontaneously clear the infection, but will continue to have detectable antibodies. Clearance of the hepatitis C virus does not lead to immunity and hepatitis C re-infection can occur following re-exposure.⁸

Cure of hepatitis C infection as a result of current therapies is possible in many people. Cure is accepted as the absence of hepatitis C virus in the blood, or sustained virological response (SVR) six months after treatment completion. The most significant predictor of cure is genotype. People with genotype 2 or 3 require 24 weeks treatment and have an 80% chance of cure, while those with genotype 1 require a 48 week treatment course and have a 50% chance of cure.^{9,10} This increases to around 65% in people with genotype 1 and early liver disease. Hepatitis C treatment can have debilitating side effects and people require ongoing support during and after therapy regardless of the outcome.

The introduction of pegylated interferon and the removal of liver biopsy as a criterion for access to subsidised treatment have resulted in immediate increases in the uptake of therapy but the number of people commencing therapy remains low (around 3500 per year). There is a need to make sure that people with hepatitis C are aware of the dramatic improvements to treatment efficacy over the past decade¹¹ and that they can access treatment without structural health system barriers. Improving access to clinical and community support organisations is critical to assist people with hepatitis C to make healthy lifestyle choices and improve their physical, emotional and social wellbeing. Hepatocellular carcinoma is a recognised feature of advanced hepatitis C and is associated with its own considerable physical and social morbidities.

A key challenge for the Australian response to hepatitis C is to further reduce transmission. This requires ongoing commitment to prevention strategies using harm reduction approaches. Acknowledging the social ramifications of hepatitis C infection, particularly the stigma and discrimination associated with hepatitis C and the barriers it creates to individuals accessing prevention education, care, support and treatment, underpins all the activities outlined in this National Hepatitis C Strategy 2010 – 2013.

The partnership approach is fundamental to this National Hepatitis C Strategy 2010 – 2013. It recognises that collaborative efforts involving all levels of government, community-based organisations, including peer-based organisations, the medical and nursing workforce, 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. The partnership approach is based on a commitment to consultation, joint decision making and action, and acknowledges and values the specific expertise which each partner contributes to the national response. This approach also acknowledges that there are opportunities to reduce the incidence and health impact of hepatitis C through collaboration across the whole of government, as well as with non-government partners.

2. Goal

The goal of the National Hepatitis C Strategy 2010-2013 is to reduce the transmission of, and morbidity and mortality caused by, hepatitis C and to minimise the personal and social impact of hepatitis C.

3. Objectives and indicators

This section details objectives and indicators for use in monitoring progress under the strategy. Indicators are measurable targets that apply to the related objective. The primary indicators are those that have been agreed under the National Healthcare Agreement (NHCA). These have been specified and will be regularly reported during the life of the agreement. Additional indicators have been included for the more specific objectives relevant to this strategy. Further work will be undertaken during the implementation phase to develop a surveillance and monitoring plan. This will include further work on specifications for the indicators, and development of an agreed process for reporting them. In some circumstances further data development may also be needed.

GOAL	OBJECTIVE	PROPOSED INDICATOR ⁽¹⁾
Reduce the transmission of hepatitis C	Reduce the incidence of hepatitis C	Incidence of hepatitis C (National Healthcare Agreement)
	Increase access to new injecting equipment through needle and syringe programs	Per capita rate of needles and syringes distributed in the public and pharmacy sector in the previous twelve months (National Healthcare Agreement) Proportion of people who inject drugs who report re-using another's used needle and syringe in the last month
Reduce the morbidity and mortality caused by hepatitis C	Reduce the burden of disease attributed to chronic hepatitis C	Estimated number of people with hepatitis C infection by stage of liver disease: <ul style="list-style-type: none"> • Chronic hepatitis C infection with stage F0/1 liver disease • Chronic hepatitis C infection with stage F2/3 liver disease • Living with hepatitis C-related cirrhosis Self-reported health status by people with hepatitis C
	Increase access to clinical care for people with chronic hepatitis C	Proportion of people with chronic hepatitis C dispensed drugs for hepatitis C infection through the Highly Specialised Drugs (s100) Program in the previous twelve months

Minimise the personal and social impact of hepatitis C	Reduce hepatitis C related stigma and discrimination in health care settings	Proportion of people with hepatitis C who report experiences of discrimination in health care settings
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(1) In areas where data are available

4. Guiding principles

The principles informing this Strategy are drawn from Australia's efforts over time to respond to the challenges, threats and impacts of HIV, STIs and hepatitis C. Strategies addressing each of these conditions, including as they relate to Aboriginal and Torres Strait Islander Australians, seek to minimise the transmission and impacts of these diseases on individuals and communities. The respective Strategies establish directions based on the unique epidemiology, natural history and public health imperatives of the diseases.

The guiding principles underpinning Australia's response to HIV, STIs and viral hepatitis are:

- The transmission of HIV, STIs and hepatitis C is preventable through adoption and maintenance of protective behaviours. Vaccination is the most effective means of preventing the transmission of hepatitis B. Vaccination, education and prevention programs, together with access to the means of prevention, are prerequisites to the adoption and application of prevention measures. Individuals and communities have a mutual responsibility to prevent themselves and others from becoming infected.
- The principles and actions described in the Ottawa Charter provide the framework for effective HIV, STI and viral hepatitis health promotion action and facilitate:
 - the active participation of affected communities and individuals, including peer education and community ownership to increase their influence over the determinants of their health; and
 - the formulation and application of law and public policy that support and encourage healthy behaviours and respect human rights as this protects those who are vulnerable or marginalised, promotes confidence in the system and secures support for initiatives.
- Harm reduction principles underpin effective measures to prevent transmission of HIV and viral hepatitis, including the needle and syringe program and drug treatment programs.
- People with HIV, STIs and viral hepatitis have a right to participate in the community without experience of stigma or discrimination, and have the same rights to comprehensive and appropriate health care as other members of the community, including the right to the confidential and sensitive handling of personal and medical information.
- An effective partnership of affected communities, Government, researchers and health professionals is characterised by consultation, cooperative effort, respectful dialogue and action to achieve the Strategy's goal and includes:

- non-partisan support for the pragmatic social policy measures necessary to control HIV, STIs and viral hepatitis;
- recognition that those living with and at risk of infection are experts in their own experience and are best placed to inform efforts that address their own education and support needs;
- timely and quality research and surveillance to provide the necessary evidence base for action;
- a skilled and supported workforce; and
- leadership from the Australian Government, the full cooperative efforts of all members of the partnership to implement the Strategy's agreed directions, and early adoption of a framework for monitoring and evaluation action.

5. Priority populations

People most affected by hepatitis C are often best placed to respond to its impacts. The importance of continued co-operation and participation of those who are living with, those at risk of, and those affected by hepatitis C is recognised. Shared efforts to prevent further transmission and to provide quality treatment, care and support to those living with hepatitis C is integral to this Strategy. The priority population groups detailed below are not mutually exclusive. Many individual members of one priority population may also be members of other priority populations.

5.1 People with hepatitis C

People living with hepatitis C are a priority for all action areas. The needs and human rights of people living with hepatitis C are central concerns of this Strategy, which recognises that people living with hepatitis C are a diverse group.

In Australia, hepatitis C is predominantly contracted through sharing used injecting equipment, although transmission through other routes also occurs. This Strategy recognises and supports the inclusion of all people with hepatitis C in prevention, treatment, care and support initiatives.

Enhanced hepatitis C treatment and support services should emphasise the additional needs of priority populations: people who inject drugs, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds and people in correctional settings.

5.2 People who inject drugs

People who inject drugs are the highest priority population of people at risk of hepatitis C infection and for hepatitis C prevention efforts. They also comprise a significant proportion of people living with hepatitis C and are a significant priority population in terms of care, treatment, and support. Approximately 90% of new and 80% of existing hepatitis C infections are attributable to injecting drug use. People who inject drugs have education and support needs in relation to hepatitis C that can be addressed by access to sterile injecting equipment and harm reduction services, appropriately targeted injecting drug user peer education and information and support in relation to testing, diagnosis and management, including treatment.

Evidence from surveys of people who access injecting equipment exclusively from pharmacies, show higher rates of re-use of equipment than those people who access equipment exclusively from NSP, supporting both the importance of NSP and that access to peer education can assist in this regard.¹²

The diversity within the population of people who inject drugs is also recognised. Recent evidence suggests that people from culturally and linguistically diverse (CALD) communities who inject drugs are at greater risk of exposure to hepatitis C because of their higher levels of social isolation and low knowledge of BBV.¹³

Aboriginal and Torres Strait Islander people who inject drugs have significantly higher rates of hepatitis C. Lack of access to equipment, community attitudes and fear of stigma or discrimination can severely hinder hepatitis C prevention and treatment efforts particularly in rural and remote communities.

Women who inject drugs are believed to be at increased risk of hepatitis C infection due to power dynamics that often exist between men and women in social networks and injecting practices.¹⁴ This extends to a lack of power in decision making about injecting practices and women's status in the hierarchy of injecting networks.^{15,16} Women in each of the priority populations are highlighted as having special needs, such as young women who inject, women from CALD backgrounds, women in custodial settings and women in rural and remote areas.

People who have been exposed to hepatitis C in the past through injecting drug use may not recognise their exposure risk. Stigma associated with injecting drug use, and fear of discrimination can make it difficult for people with a history of injecting drug use to access hepatitis C diagnosis and management. Undiagnosed, chronic hepatitis C will cause progressive liver disease¹⁷ and associated morbidity and treatment complications. Australia has very high rates of hepatitis C diagnosis, but primary care providers need to remain vigilant to the potential for hepatitis C, particularly in patients with any signs of liver disease irrespective of assumptions about a patient's risk of exposure.

5.2.1 Aboriginal and Torres Strait Islander people who inject drugs

The *National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy 2010 - 2013* has also prioritised the reduction of BBV transmission associated with injecting drug use, in response to recent rises in hepatitis C infections. Successive strategies have cautioned about the potential for HIV to become endemic in Aboriginal and Torres Strait Islander communities. While this situation has not eventuated, increases in hepatitis C infection among Aboriginal and Torres Strait Islander people suggest that this could happen.¹⁸

Aboriginal and Torres Strait Islander people who inject drugs have a higher incidence of hepatitis C than other Australians. Aboriginal and Torres Strait Islander people are significantly over-represented in adult and juvenile custodial settings, which compounds their risk of exposure to hepatitis C. Reporting of Indigenous status remains inadequate, therefore, estimates of population prevalence are difficult, but would appear to be three-fold higher than the non-Indigenous population.¹⁹

Aboriginal and Torres Strait Islander people may progress to hepatitis C-associated liver disease faster than other populations because of chronic disease and other risk factors. Ensuring access to culturally appropriate harm reduction, injecting drug user peer education, health care and social welfare services is imperative to reduce the impact of hepatitis C on the community.

5.2.2 People at risk of hepatitis C infection as new, or potential injectors

People who are new to injecting are also a high priority population for hepatitis C prevention initiatives. While there is some variability in research results, the median age of initiation to injecting drug use is between 17 and 18 years old.^{20,21} Young people have a greater dependence on others for administration of their first injection and obtaining injecting equipment.^{22,23,24} There is a high risk of contracting hepatitis C shortly after the onset of injecting.²⁵ It is therefore essential that people new to injecting: have access to education about hepatitis C; understand the routes of transmission and the high risk of hepatitis C associated with injecting compared to other modes of drug administration; are supported to develop skills to prevent exposure to hepatitis C; and have access to sterile injecting equipment in order to reduce their risk of acquiring hepatitis C.

Young people are also at risk of hepatitis C and other BBVs and STIs as a result of risk taking behaviour and a lack of understanding about the routes of transmission and the possible consequences of their actions. People can also be placed at risk of contracting hepatitis C and other blood borne viruses through unsafe piercing and tattooing. As piercing and tattooing is common in young people, it is important that they gain an understanding of how hepatitis C and other blood borne viruses can be transmitted.

5.3 People in custodial settings

People in custodial settings are at increased risk of exposure to hepatitis C because of the high number of people in prison for drug-related offences, the high prevalence of hepatitis C in prison populations and associated use of un-sterile injecting equipment, and sharing of tattooing and piercing equipment and other blood-to-blood contact. The combination of the transmission of hepatitis C in custodial settings and prisoner recidivism presents a challenge to controlling hepatitis C infection both within these settings and in the broader community.²⁶

Two priority populations known to be at risk for hepatitis C exposure are significantly over represented in custodial settings, namely people who inject drugs and Aboriginal and Torres Strait Islander people (24% of Australia's prison population are Aboriginal and Torres Strait Islander people). The 2007 National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey²⁷ found that 35% of prisoners tested positive to hepatitis C antibodies, forty times higher than that found in the general population, and significantly higher than that found in juvenile justice facilities.²⁸

Initiating hepatitis C prevention and treatment measures in custodial settings is hampered by structural barriers including lack of capacity to implement the full range of evidence-based harm reduction interventions, particularly NSPs which is a critical element of the national response to hepatitis C.^{29,30} However, custodial settings can provide people at high risk of infection access to education, diagnosis and treatment as well as screening for other BBV, particularly hepatitis B and vaccination where indicated.³¹

Each state and territory has its own separate, independent system of police, courts, prisons and juvenile institutions. Health services are provided variously by health or justice jurisdictions and supplied directly, or contracted, by public and private custodial facilities. Australia's prison systems are relatively small and isolated from each other. This presents challenges for the coordination of policy development, implementation and evaluation, research and education. However these challenges have been overcome within the custodial environment to enable effective responses to a number of key public health issues including BBV and STI initiatives such as provision of condoms, access to bleach, provision of opioid pharmacotherapies, the National Prison Entrants BBV & Risk Behaviour Survey, etc.

The provision of sterile injecting equipment in Australian prisons is a controversial issue for some in the community. An increasing number of international jurisdictions have implemented or are actively contemplating the implementation of needle and syringe programs in prisons. To date there is no evidence of adverse outcomes associated with these programs. However, several positive or beneficial outcomes have been documented from programs that have undergone evaluation, including: no documented increase in illicit or injecting drug use; significant reductions in equipment reusing/sharing; no documented attacks or violence; no documented seroconversion for HIV or hepatitis; and acceptance of the program by staff and prisoners.

In view of the well documented return on investment and effectiveness of Australian community-based needle and syringe programs, combined with the international evidence demonstrating the effectiveness of prison needle and syringe programs it is appropriate throughout the life of this strategy for State and Territory Governments to identify opportunities for trialling the intervention in Australian custodial settings.

In addition to identifying opportunities for trialling needle and syringe programs in prisons, it is also essential that the full range of BBV & STI prevention strategies are maintained in Australian custodial settings, including:

- Increasing the provision of, and access to bleach and disinfectants where no other safer alternatives are provided for decontaminating spills, surfaces or equipment;
- Easily accessible education and counselling including peer education and support on HIV & STIs, hepatitis B and hepatitis C and injection drug use as a fundamental health promotion technique to support risk reduction practices; and
- increasing access to drug treatment programs including opioid pharmacotherapy programs which have been demonstrated to reduce blood borne virus transmission in custodial settings as well as detoxification and drug rehabilitation programs.

Strategies should also be explored for developing and promoting Australian infection control standards for tattooing and body art to reduce the risk of transmission of blood borne viruses via those means in custodial settings.

5.4 People from culturally and linguistically diverse backgrounds

People from CALD backgrounds are a diverse group comprising people of all ages, some from high hepatitis C prevalence regions of the world³². It is estimated that 15-20% of people with hepatitis C remain undiagnosed, many of whom will be from countries of high hepatitis C prevalence. In addition, many people from CALD communities may be diagnosed late and may have advanced hepatitis C-related liver disease.³³

People with hepatitis C from CALD backgrounds have unique information and support needs. The diversity within the communities must be acknowledged in the development and delivery of culturally appropriate services. Newly arrived refugees and members of emerging communities share many of the same needs as established CALD communities, though it is worth highlighting that, due to competing social, financial and physical needs associated with settlement in Australia, people from emerging and migrant communities may be less likely to prioritise their health and hepatitis C.

Priority CALD communities for hepatitis C can be identified by giving consideration to evidence including:

- hepatitis C prevalence in countries-of-birth with a greater emphasis on those countries where prevalence is high;
- census and immigration data and trends; and
- consultation with community organisations and multicultural health services.

As with other targeted programs, prevention, treatment and care initiatives for these populations should be developed and implemented in partnership with the communities themselves, in order to develop interventions and models of care that are relevant and culturally appropriate.

5.5 People with hepatitis C with co-morbidities

People with hepatitis C with co-morbid health conditions need to have access to education about hepatitis C disease progression and prevention, and the knowledge and skills to access hepatitis C treatment and care services. In particular, several subpopulations have special needs, namely those people with hepatitis C and:

- hepatitis B;
- HIV;
- hepatitis B and HIV co-infection;
- bleeding disorders;
- mental health conditions; and
- alcohol and other drug dependence.

6. Priority action areas

6.1 Prevention and education

Hepatitis C transmission is preventable. The effective implementation of prevention interventions reduces hepatitis C transmission and the subsequent impact of infection on both individuals and the community. In Australia, the majority of hepatitis C transmission occurs through unsafe injecting drug use practices. Decreasing hepatitis C transmission between people who inject drugs is therefore a priority for the partners to this Strategy.

Harm reduction is the basis of Australia's public health response to the transmission of hepatitis C and other blood borne viruses transmitted through unsafe injecting drug use practices. This approach encompasses a variety of strategies, including distribution of sterile injecting equipment, peer education, access to opioid pharmacotherapies and primary care services.

Involving people who inject drugs in prevention and education efforts is integral to the success of this strategy. Peer education and support by and for people who inject drugs is a preferred option for obtaining credible and accurate information about hepatitis C. With appropriate training and support, people with or at risk of hepatitis C, in particular people who inject drugs, are best placed to communicate prevention messages. However, peer education with marginalised groups requires an understanding of the demands on potential peer educators and appropriately designed programs which support peer educators.^{34,35,36}

Although injecting drug use is a relatively uncommon activity, young people have a higher rate of exposure to injecting drug use practices. In surveys of young people attending music festivals, approximately 25% had been offered the opportunity to inject drugs, or had a friend or partner who injected.³⁷ While only a small proportion of these young people may go on to inject drugs, they are important targets for hepatitis C prevention messages.

The legal environment affecting injecting drug use practices provides specific challenges for implementing initiatives aimed at reducing the harm associated with these practices. Several legislative barriers to broadening access to injecting equipment were identified in the Intergovernmental Committee on AIDS (IGCA) Legal Working Party report in 1992. These barriers included self-administration laws and laws making unauthorised peer distribution of sterile injecting equipment illegal. The secondary distribution of sterile injecting equipment from people who inject drugs to their peers has potential to increase access but is illegal in many jurisdictions.³⁸ There have been developments at the international level in ensuring drug policy approaches support harm reduction efforts and in addressing the negative impact criminalisation has on the health and human rights of people who inject drugs.³⁹

Modelling commissioned by the Australian Government estimated that NSPs prevented 32 000 HIV and 97 000 hepatitis C infections among people who inject drugs in the period 2000-2009. This prevention equated to \$4 directly saved for each dollar invested, saving the Australian health system a cumulative \$1.28 billion.⁴⁰ This study also indicated that expanding the program to increase distribution of sterile injecting equipment by an additional 50% could lead to maximal financial returns and would yield a further 37% decrease in HIV and 23% decrease in hepatitis C cases over the next 10 years.⁴¹

Priority actions in prevention and education:

- Increase access to sterile injecting equipment, particularly in priority populations;⁴²
- Strengthen the capacity of education providers and the providers of services to young people to ensure that they have access to harm reduction knowledge and skills;
- Strengthen collaboration with the alcohol and other drug sector;

- Enhance the capacity of the NSP workforce to engage with people with or at risk of hepatitis C infection and provide targeted education and health promotion interventions;
- Develop innovative health service delivery models, particularly targeting people who inject drugs;
- Enhance training and support for community-based hepatitis C educators including injecting drug user peer educators;
- Identify and work to address legal barriers to evidence-based prevention strategies across jurisdictions;
- Conduct a feasibility study into providing the full range of hepatitis C prevention interventions in custodial settings throughout Australia with the view to piloting the provision of prison-based NSP; and
- Continue to support, expand access to and evaluate the effectiveness of the range of opioid pharmacotherapy programs throughout Australia in reducing transmission of hepatitis C.

6.2 A human rights framework for addressing stigma and discrimination

People with and at risk of hepatitis C experience discrimination within a range of settings predominantly within the health care system, but also in employment and social networks.^{43,44,45,46} Discrimination is a barrier to accessing information, prevention, support, testing, treatment and care.^{47,48} Members of the hepatitis C priority populations may experience other types of discrimination which are then exacerbated by discrimination based on their actual or perceived hepatitis C status. The two previous National Hepatitis C Strategies recognised the impacts of stigma and discrimination. This third Strategy prioritises addressing stigma and discrimination among those most affected by hepatitis C.

In 1992 the Intergovernmental Committee on AIDS (IGCA) Legal Working Group recommendations promoted the need for policy and legislative reform to support effective responses to blood borne viruses among people who inject drugs and other priority groups. While reform has occurred in line with these recommendations in other areas including men who have sex with men and sex workers, no progress has been forthcoming in relation to people who inject drugs.

Harmonisation between drug control laws and public health policy would create a better social and legal environment for enhanced application of established hepatitis C prevention strategies among people who inject drugs.

Priority actions around stigma and discrimination:

- Develop and implement a national hepatitis C public education campaign which aims to dispel myths and misconceptions around hepatitis C and reduce the prevalence of discriminatory attitudes and behaviour in the general community and specifically within health care settings;
- Create supportive and enabling environments, promote the health and human rights of those living with or at risk of hepatitis C and support access to hepatitis C prevention, treatment and care services;
- Include information on mechanisms for reporting discriminatory practices in health care and other settings in resources developed for people living with hepatitis C and address stigma and discrimination in health care worker training; and
- Identify and work to address legal barriers to evidence-based prevention strategies across jurisdictions.

6.3 Testing and diagnosis of hepatitis C

The National Hepatitis C Testing Policy⁴⁹ benchmarks best practice standards for health professionals, people with hepatitis C, government, industry and the wider community with regard to testing and diagnosis. However, insufficient implementation of the testing policy has created poor diagnostic practices including inadequate access to pre- and post-test discussions at the time

of diagnosis, and subsequent insufficient referral to clinical and support services. There is also a lack of implementation of confirmatory HCV RNA (e.g. by PCR) testing for people who have had a positive hepatitis C antibody test. As a result, many people believe they have hepatitis C (based on a positive antibody test result) when in fact they have cleared the virus.⁵⁰

Inadequate systems exist to ensure that people at risk of hepatitis C infection are regularly screened, although data suggest that a number of NSP service users test regularly. It is estimated that there is a pool of between 40 000 and 50 000 undiagnosed people in the community, many of whom are members of hepatitis C priority populations⁵¹.

It is recognised that people with hepatitis C who inject drugs, people in custodial settings, Aboriginal and Torres Strait Islander people, people from priority CALD backgrounds, and young people often experience barriers to accessing health services. These difficulties are often compounded when seeking testing and treatment for hepatitis C. Additional resources would improve the ability of specialist and primary health care services to adapt to and meet the clinical needs of people with hepatitis C from priority populations. There is also a place for peer education and peer support in assisting people through the testing and diagnosis process.⁵²

Priority actions in testing and diagnosis of hepatitis C:

- Promote testing and treatment in line with guidelines;
- Ensure that people with or at risk of hepatitis C have access to high quality services at the time of diagnosis;
- Expand the hepatitis C Testing Policy to include hepatitis B;
- Implement targeted initiatives with priority CALD communities and health care providers with high caseloads of patients from priority CALD communities to promote awareness of and support measures to improve compliance with the National Hepatitis C Testing Policy; and
- Develop education for people who inject drugs, those on pharmacotherapy and their health care providers including all general practices and primary healthcare services to ensure that hepatitis C testing and diagnosis process is properly understood and based on informed consent.

6.4 Treatment, health and wellbeing

The number of people with hepatitis C developing advanced liver disease complications (liver failure, primary liver cancer) and dying from liver disease-related causes will continue to increase at the current treatment level (3500 per year). Approximately 6000 people each year need to be treated to stabilise the number of people progressing to advanced liver disease. An increase of treatment uptake to 6000 per year is highly cost-effective in terms of cost per quality adjusted life year (QALY) gained, with further increases to 8000 and 12 000 providing further improvements.⁵³ However, there is limited capacity in most of Australia's specialist hepatitis C treatment services to treat more people with hepatitis C and as a result waiting lists are growing in a number of jurisdictions. Greater capacity in the primary healthcare sector to contribute to service delivery in hepatitis C treatment and care is required and should be explored.

There are barriers for people from priority populations who want to access hepatitis C treatment. Barriers to accessing care and treatment for Aboriginal and Torres Strait Islander people with hepatitis C include limited knowledge of the virus; stigma and discrimination associated with hepatitis C transmission; lack of knowledge about the availability of treatment and reluctance to access mainstream services.⁵⁴ A recent report about Aboriginal and Torres Strait Islander people living in Victoria highlighted that finding the most appropriate and sustainable ways for Aboriginal and Torres Strait Islander people with hepatitis C to live well with the virus will achieve far more in reducing the burden of disease than attempting to find a model to increase the number of Aboriginal and Torres Strait Islander people in liver clinics across Australia.⁵⁵

Custodial settings have the potential to be a focal point for hepatitis C testing, education and treatment for a recognised priority population group. While Hepatitis C treatment is currently available in some custodial settings, services for hepatitis C-related health care for prisoners are not consistently available nationally.

People from CALD backgrounds often confront barriers to accessing health care related to their hepatitis C such as communication difficulties and lack of access to professional interpreting services, poor access to written information in their preferred language, limited knowledge of the Australian health care system and poor awareness of their rights. Ethnic and cultural beliefs about BBVs, the meaning of blood and the nature of treatment and illness may negatively impact on their decision to pursue hepatitis C treatment.

The integration of injecting drug user peer support and hepatitis C treatment services has been demonstrated as acceptable and feasible for people contemplating, undergoing and immediately post treatment. The evaluation of such programs shows a strong preference for support provided by other people who inject drugs who have hepatitis C⁵⁶. Other initiatives such as phone-based peer support services for people with hepatitis C, their partners and carers, and people who are considering or currently undergoing hepatitis C treatment, are highly regarded, sought after and available in some jurisdictions.

Clinical testing of protease and polymerase inhibitors in combination with pegylated interferon and ribavirin for the treatment of hepatitis C genotype 1 is currently underway. It is possible these new agents will be approved and in use during the life of this Strategy. These treatments will potentially shorten the duration of treatment and improve response rates. In that context, access to and delivery of clinical services throughout Australia is important.

Following worldwide interest in expanding hepatitis C treatment options, delivery of hepatitis C treatment in opiate pharmacotherapy settings is underway and expanding in Australia. Evaluation of these initiatives is ongoing.^{57,58}

Priority actions in treatment, health and wellbeing:

- Investigate innovative projects that increase the participation of general practitioners, nurses and other members of primary healthcare teams in the management of hepatitis C, including the delivery of treatment;
- Strengthen the capacity of existing tertiary hepatitis C treatment services to treat more people with hepatitis C and to support innovative models of care;
- Increase the participation across the health workforce in the delivery of hepatitis C management, including through the integration of peer support for people undergoing treatment and people who inject drugs; and
- Implement innovative projects to link people with hepatitis C with support services at the time of diagnosis.

6.5 Models of care and clinical management

Hepatitis C is a chronic disease for the majority of people. Clinical management pathways for people with hepatitis C provide medical practitioners, including GPs and consultant specialists, hepatology nurses, community support services and people who have hepatitis C with best practice guidelines for clinical care. The current model of care document⁵⁹, does not reflect current evidence or best practice. However, it continues to be used by health professionals and results in outdated service delivery. An updated model should give consideration to testing for hepatocellular carcinoma in advanced liver disease and include advice on the testing, management and treatment of hepatitis C in the paediatric setting.

Rates of referral from primary health care services to specialist hepatitis C treatment and care services remain low. This suggests a lack of clarity around preferred referral practices and a lack of service options for those most affected by hepatitis C. In the era of improved antiviral treatment, availability of and referral to appropriate clinical services is critical. Participation and support of primary healthcare in the delivery of hepatitis C management remains low and needs to be encouraged to increase the availability of treatment and care for people living with hepatitis C.

There is variation in the provision of hepatitis C treatment and care in custodial settings in Australia. However, custodial settings can provide people at high risk of infection access to education, diagnosis and treatment. They can also provide screening for other BBV. The *Hepatitis C Prevention, Treatment and Care: Guidelines for Australian Custodial Settings* outlines appropriate models of care for people with hepatitis C in custodial settings although these guidelines have not been implemented.

Priority actions in models of care and clinical management:

- Review and revise the *Model of care for the management of adults with chronic hepatitis C* (2003) regularly to ensure that it stays in step with clinical advancement and changes to management standards;
- Monitor implementation of the *Hepatitis C Prevention, Treatment and Care: Guidelines for Australian Custodial Settings* (Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis [MACASHH] Hepatitis C Subcommittee 2008); and
- Support GPs, nurses and other primary care providers to improve their skills in hepatitis C management, treatment and referral.

6.6 Health maintenance, care and support for people with chronic hepatitis C

People with hepatitis C are at risk of progressive liver disease. Lifestyle risk factors that make people more likely to develop progressive liver disease include heavy alcohol intake and fatty liver disease (associated with obesity). However, hepatitis C is significantly different to other chronic diseases as a cure is possible for many people, possibly 50 – 80% of those treated. But while the number of people on treatment remains as low as it is, hepatitis C remains a chronic disease for the majority.⁶⁰

People with hepatitis C therefore need to understand the information and support services available to assist them make appropriate lifestyle choices to reduce the burden associated with hepatitis C infection and improve their health outcomes. This includes obtaining information about hepatitis C and remaining up-to-date with new information in areas such as diagnosis, development of symptoms, management of symptoms, and the possibilities for preventing or slowing the progression of the disease through use of self-management strategies and antiviral treatment.

Peer-based drug user organisations and hepatitis organisations and other community-based services have the expertise and capacity to provide hepatitis C information and support in areas such as validating symptom experiences and making decisions about hepatitis C management and treatment. However, awareness of these services remains limited among people with hepatitis C and health professionals. Disclosure of hepatitis C status is an impediment to accessing support, because it can result in social isolation and discrimination and often involves people disclosing their participation in criminalised behaviours such as injecting drug use. Previous experiences of stigma, discrimination or racism can act as a barrier to accessing information, education, diagnosis support and management in relation to hepatitis C.

Priority actions in health maintenance, care and support for people with chronic hepatitis C:

- Undertake education about hepatitis C for the health, community and welfare sectors to engender a supportive social environment for people with hepatitis C and their families; and

- Provide accurate and appropriate information for people with, or at risk of hepatitis C and their support network, on the impact of infection, natural history, and self-management options including how to reduce the risk of developing liver disease and how to access specialist services, and how to exercise their legal and health rights.

7. Surveillance

Existing hepatitis C surveillance systems need to be enhanced to provide accurate data to inform the planning and delivery of prevention and disease management options.

Hepatitis C surveillance involves the systematic and continuous collection, analysis, interpretation and dissemination of hepatitis C prevalence and incidence and behavioural data. Surveillance data are used to identify people at risk of infection, the long-term outcomes of infection and provide data for governments to target and evaluate hepatitis C prevention and treatment activities.

Acute, or newly acquired, and chronic hepatitis C infection cases are routinely notified through public health surveillance systems with limited demographic information. The data are forwarded to the Australian Government's NNDSS for collation and national reporting. Notifications of newly acquired hepatitis C underestimate the true incidence of hepatitis C, while notifications of unspecified or chronic cases underestimate the burden of disease related to hepatitis C. For these reasons, the response to hepatitis C has relied on modelling of the incidence and prevalence of the disease.

Australia has one of the best surveillance systems in the world for monitoring the prevalence of HIV and hepatitis C infection among people who inject drugs.^{61 62} Since 1995, the Australian Needle and Syringe Program (NSP) Survey has provided annual estimations of point prevalence to monitor changes over time in patterns of infection and risk behaviours among NSP clients. With sample sizes ranging between 1072 (in 1995) and 2694 (in 2000), results derived from this program have demonstrated that these findings can be generalised to all Australian public sector NSP clients, with samples considered likely to be as representative as can be practically obtained.⁶³ With increased resources and new methods currently available we could potentially use these data to estimate HIV and HCV incidence in people who inject drugs.⁶⁴ However, further work is needed to document and understand the heterogeneity of people who inject drugs including those who exclusively attend pharmacy NSP outlets or rely on others to provide equipment and hence would not be part of the existing NSP surveillance systems.^{65,66}

Priority action in surveillance:

- Develop and implement a National Viral Hepatitis Surveillance Strategy under the supervision of the Communicable Diseases Network of Australia (CDNA) which facilitates the collection of demographic data, including country of birth and Indigenous Australian status and sentinel surveillance for priority populations.

8. Research

Research is critical to providing the evidence base for the development and implementation of policies and programs at all levels of the national response to hepatitis C.

The main branches of research contributing to reducing the impact of hepatitis C are basic scientific research and virology, epidemiology, clinical research, and social and behavioural research. Collaboration between these research subspecialties needs to occur to expand our

understanding of the hepatitis C epidemic, including the economic impact of various actions and inactions.

Of particular importance is the meaningful involvement of affected communities in research activities, including partnership in setting the research agenda. Future research needs to be clearly linked to the needs of the affected community.

Priority actions in research:

- Facilitate communication between basic scientific and virology, epidemiology, clinical, social and behavioural researchers and policy and program providers at the national, state and territory level and affected communities so that the evidence base is developed and appropriately applied;
- Maintain a balance between strategic research to guide the development of the national response including policy formulation and health promotion activities, and investigator-driven research which responds to unique contexts and circumstances;
- Prioritise socio-behavioural and clinical research to identify methods of overcoming the barriers to prevention, testing, diagnosis and treatment and management of hepatitis C, including identifying preferred models of care;
- Continue translational research to improve understanding of hepatitis C pathogenesis, antiviral resistance for emerging therapeutic agents and prevention strategies including vaccine development; and
- Enhance capacity for collaborative clinical research that evaluates potential improved treatment regimens, particularly those that reduce treatment duration.

9. Workforce development

The rapid increase in demand for hepatitis C prevention, diagnosis, treatment and support services has created challenges for the workforce. Many people in the health workforce received little or no pre-service training for hepatitis C.⁶⁷ All general practitioners and primary healthcare services will see people with hepatitis C or at risk of hepatitis C.

Workforce development is critical for minimising the impact of hepatitis C on the individual and the community as a whole. Easy access to information about hepatitis C transmission, testing, treatment and referral through a broad range of professionals underpins the majority of the priority action areas in the National Hepatitis C Strategy 2010 - 2013. However, many health and community sector workers lack the capacity to effectively care for and support people with hepatitis C due to low levels of hepatitis C knowledge.

Clinical, prevention and community services and organisations which support people with hepatitis C need to be adequately resourced and knowledgeable to deliver appropriate services to people with hepatitis C. Specific support should be provided to peer-education and support services.

Mainstream hepatitis C treatment services are not readily accessed by people with hepatitis C from priority populations. People with hepatitis C from CALD backgrounds, Aboriginal and Torres Strait Islander people, young people and people who inject drugs have special needs in relation to accessing hepatitis C treatment and care.

Priority actions in workforce development:

- Prioritise workforce development for the hepatitis C prevention workforce including NSP workers and alcohol and other drug workers, medical, nursing and certain allied health professionals, youth workers, the Aboriginal and Torres Strait Islander workforce, the CALD workforce and custodial workers including health professionals and custodial staff to increase awareness and understanding, reduce discrimination and improve access to those services for people who inject drugs;

- Develop and implement cultural competency training for hepatitis C treatment providers to build their capacity to work with people from CALD backgrounds and Aboriginal and Torres Strait Islander people; and
- Encourage universities and other health and education training organisations to include viral hepatitis, blood awareness, anti-discrimination and cultural awareness issues in their curricula.

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