

# **National Hepatitis B Strategy 2010 - 2013**

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## 1. Background

This is the first Hepatitis B Strategy to be adopted in Australia. It 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 First National Hepatitis B Virus (HBV) Strategy (this strategy);
- The Sixth National HIV Strategy;
- The Second National Sexually Transmissible Infections Strategy;
- The Third National Hepatitis C Virus (HCV) 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 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
- Some 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 B in Australia

Hepatitis B is a blood-borne and sexually transmitted viral infection. The virus is transmitted either through percutaneous (puncture of skin) or mucosal exposure to contaminated blood or body fluids. Serum, semen and saliva have been shown to be infectious for hepatitis B. The liver is the major site of hepatitis B viral replication.

Hepatitis B transmission occurs:

- from mother to infant at or around birth (perinatal);
- in, and between, children;
- in household settings between children and adults;
- through sexual contact;
- in health care settings, including from exposure to contaminated equipment, blood products and body tissues or fluids; or
- through the unsafe sharing of injecting equipment.

Over 2 billion people globally have been exposed to hepatitis B and an estimated 350-400 million people have chronic hepatitis B infection. Hepatitis B is a leading cause of death worldwide with most of these deaths occurring in the Asia-Pacific region.<sup>1</sup> This region currently contributes two thirds of all migration to Australia.

The number of people living with chronic hepatitis B in Australia was estimated in 2000 to be between 90 000 and 160 000, representing a prevalence rate of 0.5% to 0.8%.<sup>2</sup> The authors of the study support a national blood survey to resolve uncertainty in these estimates. A more recent survey estimates the range between

153 000 and 175 000 of people living with chronic hepatitis B,<sup>3</sup> or 186 000<sup>4</sup>. In 2008, 245 incident cases of hepatitis B and 6600 notifications of hepatitis B (unspecified) were reported to National Notifiable Diseases Surveillance System (NNDSS). By 2017, it is estimated that there will be a two to three fold increase in the number of hepatitis B-induced liver cancer cases and a marked increase in the number of deaths attributable to hepatitis B under current treatment patterns.<sup>5</sup>

The major issues relating to hepatitis B in Australia are and will remain the need to continue to prevent new infection and manage established chronic infection. This Strategy has been devised to provide guidance in the development of activities for the identification and management of undiagnosed (and therefore unmanaged) cases of hepatitis B. New hepatitis B infections in adults rarely lead to chronic infection and vaccination programs will largely prevent domestic acquisition in the longer term.

Australia has reduced the impact of hepatitis B by securing a safe blood supply; implementing a national hepatitis B immunisation program, and providing treatment for people with chronic hepatitis B through the Pharmaceutical Benefits Scheme. The National Hepatitis B Strategy 2010-2013 broadens this approach by promoting comprehensive and inclusive strategies. The involvement of communities most affected by hepatitis B is essential to all levels of the national response.

## 2. Goal

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

## 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	INDICATOR <sup>(1)</sup>
<b>To reduce the transmission of hepatitis B</b>	Reduce hepatitis B infections	Incidence of hepatitis B (National Healthcare Agreement)
		Coverage of hepatitis B vaccination among children and adolescents (Essential Vaccines National Partnership Agreement)
<b>To reduce the morbidity and mortality caused by hepatitis B</b>	Reduce the proportion of people with chronic hepatitis B who have not been diagnosed	Estimated proportion of people with chronic hepatitis B who have not been diagnosed

<b>To minimise the personal and social impact of hepatitis B</b>		Notifications of acute and unspecified hepatitis
		Proportion of people who die from hepatocellular carcinoma within 12 months of hepatitis B diagnosis
	Improve the health and wellbeing of people with chronic hepatitis B, through access to clinical services, screening, treatment, education and support	Proportion of people with chronic hepatitis B who meet criteria for hepatocellular carcinoma who are receiving annual screening
		Incidence of hepatocellular carcinoma attributed to hepatitis B
		Proportion of people with chronic hepatitis B dispensed drugs for hepatitis B infection through the Highly Specialised Drugs (s100) Program

(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:
  - o 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
  - o 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:
  - o non-partisan support for the pragmatic social policy measures necessary to control HIV, STIs and viral hepatitis;
  - o 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;
  - o timely and quality research and surveillance to provide the necessary evidence base for action;
  - o a skilled and supported workforce; and
  - o 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

Unlike hepatitis C, HIV and the STIs predominantly addressed in this suite of strategies, hepatitis B can be prevented by vaccine. The vaccine prevents new infections, which is particularly important in newborns and children as they have a greater risk of adverse events and disease progression if infected with hepatitis B. The importance of childhood vaccination is recognised by its inclusion in the National Immunisation Program Schedule. Activities that aim to reduce the burden of disease for those with existing chronic infection are also discussed in this strategy.

The greatest burden of hepatitis B is borne by people who already have established hepatitis B infection (chronic infection). Many of these individuals will have become infected at birth or as children and many may be unaware of their infection. As a result there are a further set of priorities explored in this strategy which relate to the detection and subsequent management of chronic hepatitis B.

Three populations are prioritised for prevention of hepatitis B transmission in this strategy:

- People from Culturally and Linguistically Diverse (CALD) backgrounds;
- Aboriginal and Torres Strait Islander people; and
- Children born to mothers with chronic hepatitis B (pregnant women).

Other populations of interest for the prevention of hepatitis B transmission in this strategy include:

- Unvaccinated adults at higher risk of infection specifically:
  - Men who have sex with men;
  - Sex workers;
  - People who inject drugs;
  - Partners and other household and intimate contacts of people who have chronic hepatitis B infection;
  - People in custodial settings; and
  - People with human immunodeficiency virus (HIV) or hepatitis C, or both.
- Health care workers and emergency services workers;
- People travelling to and from high prevalence countries, particularly people visiting families and friends in their country of origin; and
- Vulnerable populations including the homeless and people with mental health issues.

Two populations are prioritised for detection, monitoring and treatment of chronic hepatitis B in this strategy:

- People from CALD backgrounds; and
- Aboriginal and Torres Strait Islander people.

All people with chronic hepatitis B require monitoring to determine whether or not treatment is required and to detect early signs of hepatitis B-related liver disease. People at risk of, or with, chronic hepatitis B infection come from a diverse cross-section of ethnic and social backgrounds, and hepatitis B infection often exists in communities acknowledged as having less access to general health services.

The variation in migration patterns within Australia and of existing infrastructure available for specific communities means that the implementation of interventions for specific communities needs to occur at local levels to take into account these variations. The implementation plan for this Strategy details interventions which acknowledge these variations.

There is a need to ensure that, by identifying and naming the specific population groups most affected by chronic hepatitis B, stigmatisation of these groups does not occur. Stigmatisation of any of the groups affected could reduce patient access to health care and consequently increase the burden of chronic hepatitis B on the Australian community. The remainder of this chapter provides further information about priority populations for prevention of hepatitis B transmission and priority populations for the detection, monitoring and treatment of chronic hepatitis B.

### **5.1 People from culturally and linguistically diverse backgrounds (CALD)**

Hepatitis B disproportionately affects people from low and middle income countries. In these countries, high rates of chronic hepatitis B are related to high levels of mother-to-child and early childhood transmission due to a lack of comprehensive immunisation programs and a secure blood supply. Priority CALD communities for hepatitis B can be identified by giving consideration to evidence including:

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

Estimates of the prevalence of hepatitis B in Australia among people from CALD backgrounds are generally consistent with the prevalence of hepatitis B in the countries of origin.

Table 1: Compares prevalence of chronic hepatitis B in country of birth and in Australia & estimates burden of chronic hepatitis B among Australians born overseas

Country	Prevalence of chronic hepatitis B in country <sup>1</sup> (%)	Estimated residential population (ERP) by country of birth (% of total Australian population) <sup>2</sup>	Estimate of chronic hepatitis B <sup>3</sup> among overseas-born Australians
China	10.7 - 11.8	313 572 (1.5)	35 300
Fiji	9.0 - 11.8	59 241 (0.3)	6 200
Hong Kong	7.7 - 11.8	87 510 (0.4)	8 500
India	2.6 – 3.6	239 295 (1.1)	7 400
Indonesia	7.2 - 9.0	64 567 (0.3)	5 200
Malaysia	6.0 - 9.0	120 053 (0.6)	9 000
Philippines	7.0 - 9.0	155 124 (0.7)	12 400
South Korea	5.0 - 11.8	78 260 (0.4)	6 600
Taiwan	10.6 - 11.8	32 394 (0.2)	3 600
Thailand	8.7 - 9.0	43 047 (0.2)	3 800
Vietnam	10.5 - 11.8	193 288 (0.9)	21 600

(1) Chronic hepatitis B prevalence estimates based on seroprevalence studies in countries of origin

(2) Australian Bureau of Statistics, Migration, Australia 3412.0, 2007-08

(3) Estimate of chronic hepatitis B based on prevalence estimate or midpoint of prevalence range, with rounding to closest 100

In describing the experience of people living with chronic hepatitis B, the National Hepatitis B Needs Assessment 2008 found that:

- communities most affected by chronic hepatitis B in Australia have often experienced highly disrupted lives and limited or non-existent access to health care services in their countries of origin;
- people with hepatitis B report their diagnosis as 'shocking' reflecting a lack of preparation for a possible positive diagnosis or of pre or post test discussion; and
- communities play an important role in providing information about hepatitis B and that few resources are available for people with hepatitis B or their families that would assist in understanding their infection and how to promote their health and wellbeing.

## 5.2 Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander Australians constitute an estimated 16% of people in Australia who live with chronic hepatitis B in spite of these communities representing 2% of the Australian population.

The prevalence of chronic hepatitis B among Aboriginal and Torres Strait Islander Australians varies according to place of residence, with estimates varying from 2% for urban Aboriginal and Torres Strait Islander populations to 8% for rural Aboriginal and Torres Strait Islander populations with remote Aboriginal communities likely to have higher prevalence rates and higher rates of liver cancer.<sup>4</sup> A study from Darwin in 2003 found an overall prevalence of hepatitis B surface antigen in Aboriginal and Torres Strait Islander pregnant women of 4.07% and non-indigenous women of 1.16%.<sup>5</sup>

Differences have been identified between Aboriginal and Torres Strait Islander and non-indigenous notifications of chronic hepatitis B with age standardised rates of 89 per 100 000 in 2004 and 114 per 100 000 in 2005 found in Aboriginal and Torres Strait Islander people, versus 15 in 2004 and 16 in 2005 per 100 000 in the non-indigenous population. Significantly higher rates were found among Aboriginal and Torres Strait Islander people in remote areas (153 per 100 000) compared to rural (24 per 100 000) and metropolitan areas (47.5 per 100 000).<sup>6</sup>

Death rates for all causes of chronic liver disease and cirrhosis between 1991 and 1995 were 4 and 5.5 times higher for Aboriginal and Torres Strait Islander men and women respectively compared to the general Australian population.<sup>7</sup> While few clinical specialists report treating Aboriginal or Torres Strait Islander people, Alice Springs Hospital report Aboriginal people dying as a result of chronic hepatitis B infection.<sup>8</sup>

## 5.3 Children born to mothers with chronic hepatitis B and children with chronic hepatitis B

While 95% of adults clear initial hepatitis B infection, only 10% of neonates and children clear initial infection, thus having chronic hepatitis B throughout their lives. People acquiring the infection early in life therefore have a higher lifetime risk of advanced liver disease. It is therefore crucial to promote screening of pregnant women for hepatitis B infection as recommended in the Australian and New Zealand Chronic Hepatitis B Recommendations to allow intervention to prevent transmission from mother to child.<sup>9</sup> Furthermore, any woman diagnosed with chronic hepatitis B should be referred to a clinician with expertise in managing viral hepatitis during pregnancy. Recent Australian evidence suggests that transmission occurs in approximately 10% of women diagnosed antenatally.<sup>10</sup>

Any child born to a mother with chronic hepatitis B should be assessed for chronic hepatitis B infection after the course of vaccination has been completed. Any children diagnosed with chronic hepatitis B should be referred to a paediatric service with expertise in viral hepatitis. Although most will have minimal liver disease early in life, this is not true for all children with chronic infection.<sup>11</sup> A recent study reported that referral of these children for assessment is rarely occurring in Australia.<sup>12</sup>

## 5.4 Unvaccinated adults at higher risk of infection

This population of interest for the prevention of hepatitis B transmission includes:

- Men who have sex with men;

- Sex workers;
- People who inject drugs;
- Partners and other intimate contacts of people who have chronic hepatitis B infection;
- People in custodial settings;
- People with human immunodeficiency virus (HIV) or hepatitis C, or both; and
- Partners and other household contacts of people with chronic hepatitis B infection.

Whilst the potential to progress from acute to chronic hepatitis B infection diminishes significantly following childhood, some unvaccinated adults remain at particular risk of hepatitis B infection and continue to have a low risk of progressing to chronic infection. More than 40% of acute hepatitis B cases are attributable to injecting drug use, reflecting low levels of vaccine uptake among this population. Men who have sex with men and sex workers are at increased risk of infection particularly if they are engaging in unprotected sex.

Protection against co-infection with hepatitis B is a priority for people with existing HIV or chronic hepatitis C due to the increased individual impact of disease for those living with co-infections. People entering custodial settings have higher rates of previous hepatitis B infection compared to the general community but only around 50% of people entering custodial settings have immunity to hepatitis B. Household or sexual contacts of people recently diagnosed with hepatitis B are also at increased risk of exposure to the hepatitis B virus.

## 6. Priority action areas

This National Hepatitis B Strategy 2010-2013 has five priority action areas:

- Building partnerships and strengthening community action;
- Preventing hepatitis B infection;
- Optimising diagnosis and screening;
- Improving the health of people with chronic hepatitis B; and
- Developing health maintenance, care and support.

This is Australia's first nationally co-ordinated response to hepatitis B and there is significant groundwork needed to support its implementation. Data available to guide the development and implementation of the National Hepatitis B Strategy are limited. The development of an evidence base from which the health care system can respond effectively and efficiently is essential.

Stigma and discrimination have been unfortunate responses to other BBVs. Many of the interventions supported by this strategy seek to directly or indirectly lessen the development of stigma and discrimination. There is at present a lack of evidence about the impact of stigma and discrimination in relation to hepatitis B which should be addressed to better inform a nationally co-ordinated response to hepatitis B.

### 6.1 Building partnerships and strengthening community action

Effective implementation of all aspects of the National Hepatitis B Strategy will only occur by engaging with communities most affected by hepatitis B. An effective national response recognises the necessity for collaboration between communities most affected by the virus and all levels of government; community-based

organisations, and the medical, health care, research and scientific communities at local, state, territory and national levels.

Epidemiological information reveals great diversity in the population groups within communities at higher risk of transmission of hepatitis B and the effects of chronic hepatitis B infection. Social exclusion and isolation affect the health status of communities from culturally and linguistically diverse backgrounds, some of which are also coping with other social hardships. Language differences and cultural health beliefs and practices influence health literacy, including access to health services.

CALD communities may have different understandings of liver disease, including the transmission of viruses, which operate outside of the paradigm of Western medicine. This fundamentally affects health literacy and the willingness or ability to access medical care. These understandings of hepatitis B within communities most affected by hepatitis B, necessitate providing education and information about hepatitis B using culturally appropriate methods.

In most jurisdictions, partnership forums including ministerial or departmental advisory structures provide advice from key stakeholders in relation to BBVs such as HIV and hepatitis C. The partnership approach acknowledges that collaboration should occur across the whole of government, including health, immigration, justice, housing, welfare, income support, education and community service agencies.

General practitioners providing care to the CALD communities most at risk of chronic hepatitis B also provide a link to these communities for targeted health promotion interventions. Engagement with these health service providers and their representative bodies is crucial to a nationally co-ordinated response.

The complexity of chronic hepatitis B for organisations already involved in national responses to BBVs requires support for the development of their expertise in hepatitis B and the culturally-based issues affecting the response.

***Priority actions around building partnerships and strengthening community action:***

- Increase access to clinical services;
- Map and identify partners to be included in local, state, territory and national responses to chronic hepatitis B;
- Develop partnerships between BBV committees and organisations representing communities most at risk of chronic hepatitis B infection at local, state and territory, and national levels;
- Support Aboriginal and Torres Strait Islander health organisations to develop their capacity and expertise in hepatitis B; and
- Develop health promotion interventions to support people with chronic hepatitis B and their families to;
  - build health literacy;
  - create supportive environments in which it is safe to disclose hepatitis B infection; and
  - support their clinical and non-clinical needs.

## 6.2 Preventing hepatitis B transmission

Hepatitis B transmission is preventable through hepatitis B vaccination. Effective implementation of the vaccination program will largely eradicate transmission and the subsequent impact of infection.

The hepatitis B vaccine is available through the Immunise Australia Program for infants at birth, 2, 4, 6 and 12 months and in children aged 10 – 13 years. Identification of mothers with chronic hepatitis B during pregnancy is essential to reduce transmission to the newborn and to provide care to the mother.<sup>13</sup> This will also provide an opportunity for vaccination of household contacts.

Levels of knowledge about hepatitis B are poor among people who inject drugs who are often unaware of hepatitis B vaccination<sup>14</sup> and do not complete vaccination regimens.<sup>15</sup> There is evidence of efficacy with an accelerated vaccination schedule which may make vaccination more accessible.<sup>16</sup> Needle and syringe programs (NSPs) may also play a role in assessing hepatitis B virus status and providing vaccination where indicated.

There is a lack of consistency between jurisdictions in the level of publicly available information through departmental websites about access to funded hepatitis B vaccination, resulting in at-risk communities not being aware of the availability of funded vaccination. Better awareness on availability of vaccination would enable effective promotion through peer education to both people who inject drugs and sex workers through integrated safe sex and safe injecting health promotion and education interventions.

As well as efforts to promote the vaccination broadly, opportunistic hepatitis B testing and vaccination in young people should be considered, particularly for young people with multiple risk factors or who may have missed childhood vaccination. This could be incorporated into Adult Health Checks for Aboriginal and Torres Strait Islander people; on engagement with the juvenile justice system; and in association with recruitment activities such as is the case with the Australian Defence Force.

Improving the capacity of countries in our region, and particularly in countries with a greater hepatitis B burden, to develop and successfully implement immunisation campaigns will have a long-term systemic impact on reducing the burden of hepatitis B on the Australian community.

### ***Priority actions in prevention:***

- Promote national consistency in groups and communities eligible for funded vaccination with priority to communities at greatest risk of hepatitis B infection;
- Increase the uptake of hepatitis B vaccination among priority populations, thereby reducing the social impact, morbidity and mortality associated with undetected or untreated infection;
- Increase awareness of hepatitis B prevention through integrated health promotion interventions promoting safe sex and safe injecting; and
- Identify an appropriate follow-up schedule for children born to at-risk mothers and promote appropriate monitoring.

## 6.3 Testing, diagnosis and practitioner initiated testing or screening

Appropriate screening, and a co-ordinated and consistent hepatitis B diagnostic testing process, will reduce the impact of hepatitis B infection. The diagnostic event provides people with chronic hepatitis B with relevant and accurate information about

their infection. Unlike other BBVs, no formal process exists for providing a chronic hepatitis B diagnosis.

Ninety-five percent of all hepatitis B notifications are for chronic hepatitis B. The primary public health response to hepatitis B notifications is the follow-up of cases of acute hepatitis B infection, and yet approximately one third of people with chronic hepatitis B are undiagnosed.

Late diagnosis has a significant impact on mortality and morbidity with one quarter of all hepatitis B-related deaths in one study occurring within six months of notification. Changes in our understanding of hepatitis B means that the concept of 'healthy carriers' is no longer valid, and the term should not be used. Education is required, particularly targeting GPs and other clinicians, to ensure that current information regarding chronic hepatitis B, its treatment and other aspects of its management, are widely understood.

Practitioner-initiated testing, or screening, in primary health care including general practice and awareness raising in the community are the main approaches available to assist in the identification of undiagnosed chronic hepatitis B. Programs to assist practitioners in primary care to take on this role have been developed. These need to incorporate diagnosis, monitoring, support, treatment and referral and will benefit from the development of partnerships between agencies.

It is important to raise awareness of hepatitis B among medical practitioners as various drugs, including chemotherapy, can cause hepatitis B flares which can be fatal. Hepatitis B can also complicate management of a range of other conditions.

***Priority actions in testing and diagnosis:***

- Review the Hepatitis C Testing Policy (2007) and consider expanding it to a Viral Hepatitis Testing Policy to include hepatitis B testing;
- Develop a model of care that assists doctors who diagnose chronic hepatitis B to conduct appropriate follow-up testing, assessment, referral and management as appropriate; and
- Promote household (and other appropriate contact) follow up for newly diagnosed chronic and acute hepatitis B cases with specific priority to checking the immunisation profile and serostatus of household members including the prioritisation of vaccination of children in the same household.

**6.4 Clinical management of people with chronic hepatitis B**

Increasing the number of people accessing clinical management is imperative to reducing the burden of hepatitis B.

Only 2% of people with chronic hepatitis B, and very few Aboriginal and Torres Strait Islander people, receive any clinical management for their infection.<sup>17</sup> Factors contributing to low levels of treatment uptake include:

- poor understanding of hepatitis B within communities most at risk of chronic infection and by primary care practitioners;
- asymptomatic nature of chronic hepatitis B infection for most people;
- mandatory liver biopsy to obtain government-funded treatment;
- concerns about antiviral drug resistance;
- toxicity of interferon-based therapy; and
- limited infrastructure for delivery of treatment, particularly in rural and remote areas.

The goals of hepatitis B treatment are to suppress viral replication, and reduce the risk of progression to advanced liver disease and to reduce the development of complications such as liver failure or liver cancer.

Improving the health of people with chronic hepatitis B includes clinical management through antiviral therapy and regular long-term monitoring, including for the development of hepatocellular carcinoma. This process of monitoring can be challenging, particularly with expectations from patients that clinical service delivery equals the provision of pharmaceutical treatment.

Treatment options for chronic hepatitis B have expanded rapidly. These changes, in addition to the complexity of the virus, complicate the development and implementation of management algorithms, and increase the difficulty for delivering optimal treatment for both general practitioners and specialists who do not have a substantial chronic hepatitis B caseload. General practice as part of a healthcare team is central to the health care experience of people living with chronic hepatitis B. A first step to reducing the burden of hepatitis B is improving the level of awareness among primary care doctors generally.

People requiring hepatitis B management often experience a range of complex social and psychological challenges. A patient with a good understanding of the impact of chronic hepatitis B infection, the purpose of treatment and the clinical process for treatment is more likely to adhere to treatment and respond effectively to the advice of the treating doctor.

Community-based liver clinics that are physically accessible and respond to the specific needs of the patient group including trained interpreters, cross cultural training of staff, staff from similar cultural background to patients, and flexibility in the delivery of care to accommodate patients' difficulties in attending appointments are effective.<sup>18</sup>

The burden of chronic viral hepatitis on specialist liver services is increasing and existing services have lengthy waiting periods for new referrals. This situation necessitates the development of a model of care for the delivery of hepatitis B care through a range of services (including the primary care sector) and identification of mechanisms to appropriately resource service delivery.

Liver biopsy is a requirement for access to government-funded hepatitis B treatment. People without access to biopsy services are unable to access treatment which is particularly impacts upon remote Aboriginal and Torres Strait Islander communities. In addition, the cultural beliefs of some CALD communities can be in conflict with liver biopsy as a procedure.

***Priority actions in clinical management:***

- Trial innovative models of monitoring and treatment which increase access to clinical services (including increased involvement of general practitioners, nurses and other health care professionals in monitoring and follow-up) and address the needs of a range of populations including remote communities and people in custodial settings;
- Explore options for primary care practitioners to prescribe hepatitis B treatments, particularly in areas with limited access to specialist care, to free up access to specialist services for more complex management; and

- Review the evidence for removing the requirement for mandatory liver biopsy for treatment, taking into account the impact of this requirement on Aboriginal and Torres Strait Islander communities.

## **6.5 Developing health maintenance, care and support for people with hepatitis B**

An increased understanding of hepatitis B infection and support of those with hepatitis B virus infection at a personal and community level will assist in reducing the burden associated with acute and chronic hepatitis B infection and improve health outcomes.

For people with chronic hepatitis B, the knowledge and skills to understand and use information relating to disease prevention and treatment to avoid health risks and to stay healthy is essential. Such health literacy involves understanding the services available within the health system and how to access and navigate these services to achieve appropriate care. Given the complexity of chronic hepatitis B, innovative and sustainable methods of developing and providing education and support to people and communities are required.

Barriers to accessing relevant information and services for communities most affected by chronic hepatitis B include lack of English language proficiency, lack of awareness of available information and services, lack of cultural sensitivity and appropriateness of services and information, family and cultural responsibilities and obligations, social isolation, access to transport and cost.

### ***Priority actions in health maintenance, care and support:***

- Develop accurate and appropriate information for people with chronic hepatitis B informing them about the impact of infection, natural history, health promotion information including how to reduce their risk of developing liver disease and how to access specialist services and legal rights.
- Provide services, information and support by organisations working with communities with a greater prevalence of chronic hepatitis B.
- Establish forums in which lessons learnt by service providers are able to be shared.
- Use referral mechanisms between general practitioners, specialist clinics and other health and welfare services for the clinical and psychosocial needs of people with hepatitis B.
- Develop chronic disease management strategies which incorporate changes to diet, exercise and alcohol intake.
- Identify barriers to accessing hepatitis B-related information and support in rural and remote areas and custodial settings.

## **7. Surveillance and 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 chronic hepatitis B.

Limited data are available describing the impact of chronic hepatitis B, and how the communities most affected by the condition respond to this infection. The evidence base for an effective public health response to the hepatitis B epidemic will be

established through well-conducted national and international research and surveillance including the collection of death data.<sup>19</sup>

Acute and chronic hepatitis B infection cases are routinely notified through public health surveillance systems with limited demographic information. These cases are forwarded to the Australian Government's NNDSS for collation and national reporting.

Notifications of newly acquired hepatitis B underestimate the true incidence of hepatitis B, while notifications of unspecified or chronic cases underestimate the burden of disease related to hepatitis B. This mechanism is also poor in the reporting of country of birth and Aboriginal and Torres Strait Islander status.

***Priority actions in surveillance and research:***

- In the context of the development of a surveillance plan for the five national BBV and STI strategies, develop a national hepatitis B surveillance strategy, under the supervision of the Communicable Diseases Network of Australia (CDNA);
- Improve reporting of country of birth and Aboriginal and Torres Strait Islander status on routine hepatitis B notifications;
- Encourage prioritisation within national research funding bodies of socio-behavioural and clinical research to identify the barriers to access to treatment and testing for chronic hepatitis B;
- Encourage prioritisation within national research funding bodies of basic science research to improve understanding of hepatitis B pathogenesis, the identification of biomedical markers for disease progression and antiviral drug resistance; and
- Investigate the establishment of a national database to track antiviral drug resistance, including clinical correlates.

## **8. Workforce and organisational development**

Strengthening the capacity of health and community services to respond effectively to hepatitis B will reduce the chronic hepatitis B burden on Australia.

Chronic hepatitis B infection is a complex disease and services providing care and support for people with chronic hepatitis B are diverse. It is essential that these sectors have access to accurate information about hepatitis B and the skills to impart this knowledge.

General practitioners, primary healthcare teams, hospital based nurses and interpreter services have a significant role to play in the identification, monitoring, support and management of people with chronic hepatitis B infection and will play an expanding role in treatment. Some of these health care workers will not have received specific training on hepatitis B (particularly the management of the sequelae of chronic hepatitis B) in their pre-service training so catch up strategies, continuing and professional education and on-the-job training will be required to increase clinical skills and cultural competency.

Developing cultural competency requires continued and sustained collaboration with communities most affected by chronic hepatitis B. There will be organisations in which cultural competence at an individual or professional level is underpinned by

systemic and organisational commitment and capacity so that services are effectively provided to people with chronic hepatitis B.

***Priority actions in workforce and organisational development:***

- Identify research on the capacity and need for workforce development and models which may be transferable.
- Develop nationally consistent and accurate information about chronic hepatitis B for community and health sectors, including national benchmarks or minimum standards.
- Develop education on chronic viral hepatitis for the range of medical practitioners, nurses, pharmacists, other health care workers, interpreters and people working with communities most affected.

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