



National Hepatitis B Needs Assessment

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LA TROBE
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Australian Research Centre in Sex, Health and Society

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We have a chance to get it right with hepatitis B – we got it wrong with HIV, in overdrive; we got it wrong with hepatitis C, in under-drive, and there's a prospect of getting right with hepatitis B.

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Executive Summary

- Hepatitis B is arguably the most complex of the hepatitis viruses and affects up to 160,000 people living in Australia. There has been no systematic response to addressing the needs of people living with chronic hepatitis B.
- There are significant gaps in the evidence quantifying the burden of hepatitis B on individuals, the health care system and the community as whole.
- Most people with chronic hepatitis B in Australia were infected at birth or in childhood. Hepatitis B is often framed as a sexually transmitted infection among medical and public health sectors. This inconsistency has significant implications for its treatment and monitoring.
- Cultural understandings of hepatitis B inform how people interpret being infected with hepatitis B. Communities play an important role in providing information about hepatitis B.
- Communities most affected by chronic hepatitis B in Australia are often affected by the virus in a context of highly disrupted lives; where access to health care services may have been non-existent, and where hepatitis B is not seen as a priority.
- People with hepatitis B report no pre or post test discussion and little or no information provided at the point of diagnosis. This fundamentally affects how people with hepatitis B understand and respond to their infection.
- People with hepatitis B often report their diagnosis as shocking with little understanding of how infection occurred or the implications of being infected.
- There were indications that people with hepatitis B were ill-informed about their infection and that decisions made about health were based on incorrect information.
- Few resources are available for people with hepatitis B or their families that would assist in understanding their infection and how promote their health and well-being.
- Activity needs to occur to increase access to treatment, particularly for Indigenous people with hepatitis B.
- Workforce development was identified as necessary for each of the professional sectors interviewed as part of this assessment. The issues to be addressed are broad and range from the provision of basic information about hepatitis B through to the availability of treatment and cultural competency.
- There has been little proactive attention by government or the pharmaceutical industry on helping medical and public health professions adapt to the changing hepatitis B environment.
- Government resources at national, state and territory levels focus on hepatitis B prevention through the immunisation program. The immunisation program is often poorly promoted or implemented within communities most at risk of current infection.
- General practitioners surveyed in this assessment noted a need to strengthen their professional skills in managing patients with hepatitis B.

Introduction

The hepatitis B virus was identified 40 years ago, and its impact remains a major global public health challenge. Worldwide, approximately 400 million people have evidence of hepatitis B infection, the majority of whom live in the Asia-Pacific region. The burden of liver disease from existing chronic hepatitis B cases; the long latency to complications of advanced liver disease; the lack of infant vaccination programs in many high prevalence countries; limits to the catch-up vaccination of adolescents; barriers to the vaccination of high-risk adults, will mean that hepatitis B remains an enormous global challenge for many years.

It is estimated that between 90,000 to 160,000 people live with chronic hepatitis B in Australia. More than half of these were born in highly endemic countries of the Asia-Pacific region. Other high-risk groups include people born in other highly endemic regions, and Indigenous people, while a minority of people with chronic hepatitis B are men who have sex with men, and people who inject drugs.

The number of people dying as a result of chronic hepatitis B, and the number of cases of hepatitis B-related liver cancer in Australia are increasing despite improvements in antiviral therapy. The hepatitis B virus is difficult to eradicate and while only a small proportion of people with chronic hepatitis B receive treatment, these treatments are increasingly able to control replication of the virus and reduce liver disease progression.

Unlike the Australian national public health response to reducing the impact of human immunodeficiency virus (HIV) and hepatitis C upon the community, no nationally coordinated public health response to chronic hepatitis B exists. A significant gap in the national response is the documentation of the specific needs of people with chronic hepatitis B and service providers.

Project brief

The ACT-HBV (Advancing the Clinical Treatment of Hepatitis B Virus), a group predominately of clinicians, were successful in gaining an unrestricted educational grant from Bristol Myers Squibb, through the Marketing Development Group, to identify the needs of people with chronic hepatitis B. The Australian Research Centre in Sex, Health and Society (LaTrobe University) undertook the development of the National Hepatitis B Needs Assessment.

The aim of the needs assessment is to identify

- key stakeholders responding to hepatitis B in each Australian jurisdiction
- needs and gaps in service provision for people with chronic hepatitis B
- informational/educational programs and policies targeting service providers and people with chronic hepatitis B
- priorities for a nationally coordinated response to hepatitis B

Key tasks for the assessment were to

- Document the needs identified by key stakeholders in each Australian jurisdiction involved in responding to hepatitis B. These stakeholders included
 - people with hepatitis B
 - clinicians, including those from public hospital liver clinics and general practitioners
 - organisations representing people with or at risk of hepatitis B infection including Hepatitis Councils; peer based injecting drug user groups; Indigenous health services; services supporting culturally and linguistically diverse (CALD) communities, AIDS Councils and other gay health services
 - departmental representatives including those involved in vaccination programs and in the response to blood borne viruses

Methodology

Interviews

Semi-structured telephone and face to face interviews were undertaken with

- people with hepatitis B (n=20)
- clinicians (n=30)
- health department program and policy officers (n=15)
- workers from community based agencies including peer-based injecting drug user groups, hepatitis councils, people living with HIV/AIDS organisations (n=25)

Focus Groups

Four focus group interviews were held with community and health workers from CALD communities, including refugee health services (n=40).

Questionnaire

A questionnaire was distributed through the Northern Division of General Practice (Victoria) to 500 general practitioners with 95 responses received.

Ethics approval for the needs assessment was obtained from La Trobe University Human Ethics Committee and the Southern Health Human Research Ethics Committee (Victoria).

The funder of the assessment had no role in study design, data collection interpretation or the writing of the report.

Hepatitis B – the Australian context

- Between 90,000 and 160,000 people in Australia are chronically infected with hepatitis B
- The majority of people with chronic hepatitis B in Australia were born in the Asia-Pacific region
- Chronic hepatitis B is more likely to occur among people infected at birth or in infancy (90%), than for people infected as adolescents or adults (5%)
- More than 40% of acute hepatitis B cases result from unsafe injecting drug use reflecting low levels of immunisation access
- Chronic hepatitis B can be prevented with a safe and effective vaccine which became available in 1982. Universal hepatitis B immunisation for infants and for some people at high risk of infection has been implemented in Australia since 2000
- There are significant variations between Australian jurisdictions in the availability of *funded* hepatitis B vaccination to people considered at high risk of exposure, and for whom vaccination is *recommended*
- Treatment for hepatitis B is available for people with chronic hepatitis B with elevated liver enzymes and activity on liver biopsy, which is required for accessing treatment through the Pharmaceutical Benefits Scheme. An estimated 2% of people with chronic hepatitis B receive antiviral therapy
- Licensed therapies for hepatitis B treatment are interferon alfa, pegylated interferon alfa-2a, and lamivudine. Adefovir is government funded only for cases where clinical resistance to lamivudine therapy has developed
- *Hepatitis B in Australia: Responding to a Diverse Epidemic*¹ has been used, and updated, to describe the Australian context of hepatitis B

Hepatitis B transmission and virology

Hepatitis B virus is a blood-borne and sexually transmitted virus. 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.

Hepatitis B transmission occurs

- perinatal (from mother to infant at or around birth)
- to and between children
- through sexual contact
- in health care settings, including contaminated needles or blood products
- through the unsafe sharing of injecting equipment

Under exposure conditions, the hepatitis B virus enters the liver through the bloodstream. The liver is the major site of hepatitis B viral replication.

The risk of hepatitis B transmission from mother to infant during delivery is approximately 80% if the mother is HBsAg+ (surface antigen positive or chronic). The risk of transmission will be significantly reduced by the administration of Hepatitis B Immunoglobulin (HBIG) and vaccination within 12 hours of delivery.

The hepatitis B virus belongs to a family of viruses called *hepadnaviridae*. Hepatitis B is a DNA virus that uses reverse transcription as a means of copying its DNA genome. The liver damage associated with acute or chronic hepatitis B occurs as a result of attempts by the host's immune response to remove the virus from infected liver cells. The major target of the host's immunological response is the hepatitis B e antigen (HBeAg), a soluble protein secreted by the virus into the bloodstream.

Natural history of hepatitis B

The natural history of hepatitis B is dependent on several factors, the major one being the age when the person is exposed. Figure 1 shows the vast majority of infants who become infected through perinatal exposure develop chronic hepatitis B (95%), while only a minority of people exposed at an older age progress to chronic infection (5%). This has particular relevance in Australia, with the large numbers of Australians who were infected with hepatitis B through presumed perinatal exposure in their countries of birth. Although the risk of exposure to hepatitis B is high among people who inject drugs and among men who have sex with men, only a minority develop chronic hepatitis B. Adult exposure rarely leads to chronic infection.

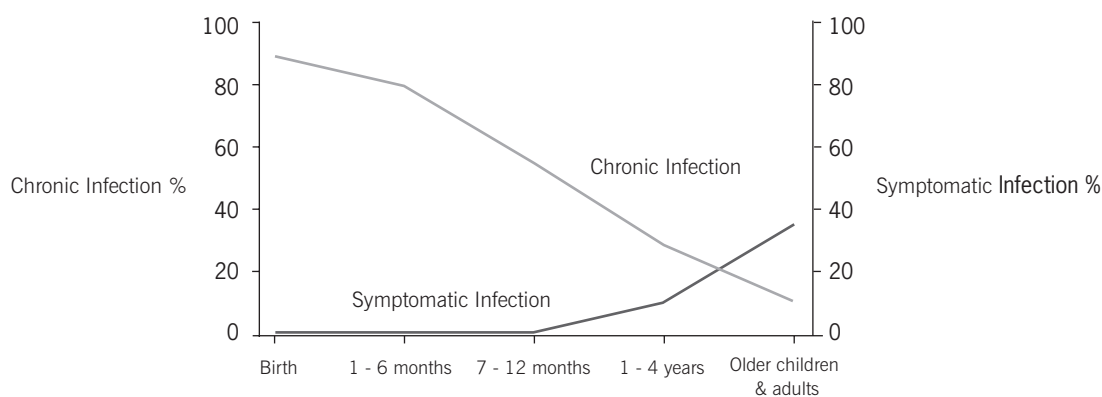


Figure 1. Outcome of hepatitis B viral infection by age at infection (sourced from World Health Organisation)

Acute hepatitis B can be either symptomatic or asymptomatic. Symptomatic hepatitis B infection is rare in the perinatal setting but is relatively common in adult-acquired infection.

Chronic hepatitis B occurs when infection with the hepatitis B virus persists and is marked by ongoing serological evidence of infection and variable liver inflammation. Persistence of HBsAg (surface antigen) for longer than 6 months has traditionally defined chronic hepatitis B. The natural history of chronic hepatitis B is highly variable, marked by alternating stages of disease inactivity and activity, and by the lack of linearity in disease progression.

Epidemiology

The number of people living with chronic hepatitis B in Australia was estimated in 2000 as between 90,000 and 160,000 and represents a population prevalence of 0.5% to 0.8%.² The major groups and the estimated proportions of people affected by hepatitis B in Australia are shown in Figure 2.

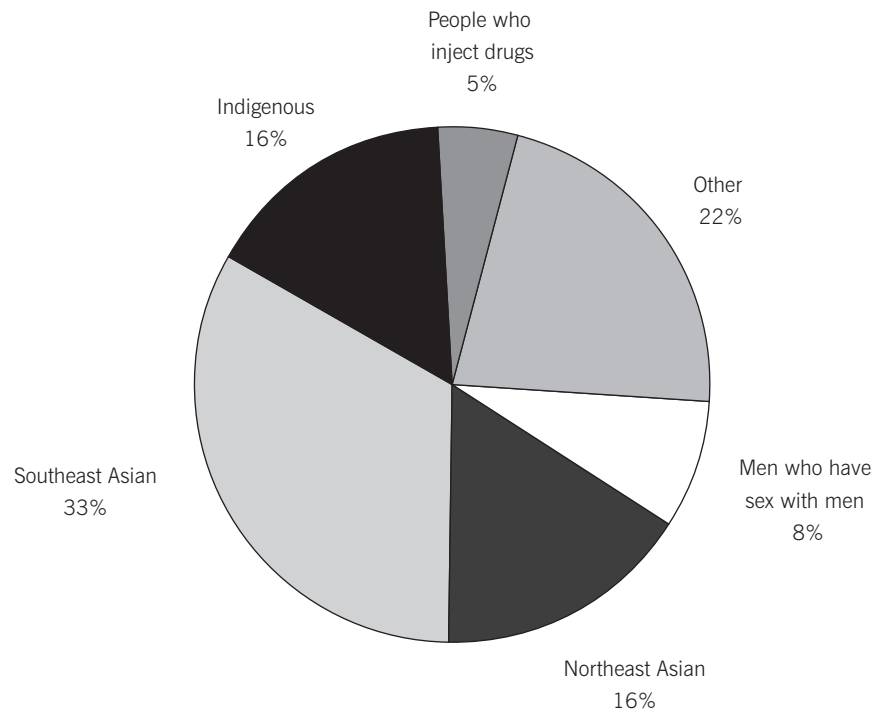


Figure 2. Estimates of chronic hepatitis B distribution in Australia. (sourced from Hepatitis B in Australia: responding to a diverse epidemic)

The majority of people with chronic hepatitis B in Australia were born in southeast and northeast Asia (49%) with other high-prevalence regions for hepatitis B including the Pacific, Mediterranean and African regions and heterosexually acquired cases related to contact with people from high prevalence countries, represented in Figure 2 by the category 'other' (22%). Other communities at higher risk of hepatitis B include Indigenous Australians, people engaging in high-risk sexual behaviour, and people who inject drugs. The authors of the study upon which these figures are based identified the need for a further national serosurvey, such as a national blood survey to resolve 'uncertainty in these estimates'.³

No large-scale population-level studies of hepatitis B prevalence have been undertaken in Australia. Notifications of chronic hepatitis B are dependent on hepatitis B testing and reporting. Current prevalence estimates rely on antenatal screening data, opportunistic laboratory surveys, and estimates of at-risk populations (with applied estimates of hepatitis B prevalence among these populations). The quality of data limits the adequacy of estimates of the number of people with chronic hepatitis B in Australia.

A recent study from a tertiary hospital in Sydney identified the strongest risk factors for hepatitis B infection to be birth in Asia or the Pacific Islands; birth in north Africa, the Middle East, and the Mediterranean region; injecting drug use; household contact with someone diagnosed with hepatitis B, and HIV infection.⁴

While people who inject drugs constitute a small proportion of the estimated number of people with chronic hepatitis B, more than 40% of acute hepatitis B cases are attributed to injecting drug use.⁵ This reflects low levels of vaccine uptake among this high-risk population.⁶ A randomised controlled trial being undertaken by the National Centre in HIV Epidemiology and Clinical Research will commence in 2008 and examine strategies to increase hepatitis B vaccination among people who inject.

In 2006, 295 incident cases of hepatitis B, and 6,296 notifications of hepatitis B (unspecified) were reported to Communicable Diseases Australia (CDA) National Notifiable Diseases Surveillance System (NNDSS) with incident hepatitis B infection in men exceeding those in women to a ratio of 1.8:1. Communicable Diseases Intelligence in their highlights for the 2nd quarter of 2007, note a 22% increase in comparison to the same period in 2006 in unspecified hepatitis B notifications.⁷

Between 1991 and 2005, approximately 90,000 notifications of 'unspecified' or chronic hepatitis B (based on the presence of hepatitis B surface antigen (HBsAg) and the absence of markers of acute hepatitis B) were received (see Figure 3). Over the same period, approximately 4,000 notifications of acute hepatitis B infection were received.⁸

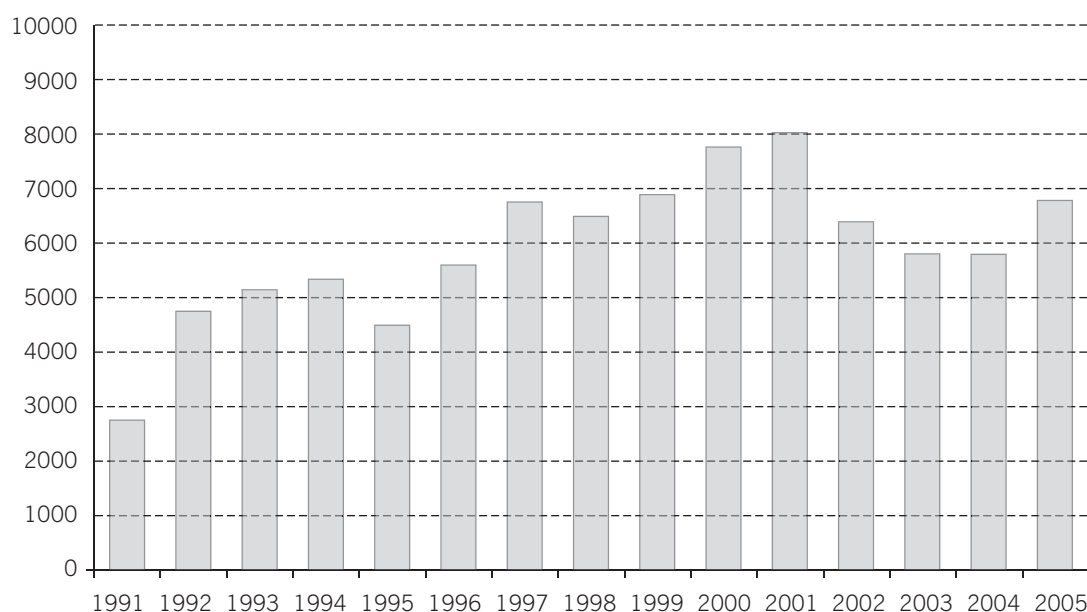


Figure 3. Notifications of chronic hepatitis B to National Notifiable Diseases Surveillance System

Incidence of liver cancer in Australia increased among overseas-born males by 90% between 1983 and 1996.⁹ Another study found liver cancer rates, the majority being associated with hepatitis B, doubling in Asian born patients between 1993 and 2003.¹⁰ Estimates that hepatitis B related liver cancer will continue to increase over the next two decades have been made,¹¹ while Roberts and Kemp note recent increases in hepatocellular cancer relating to hepatitis C and hepatitis

B infection.¹² While cancer incidence rates in people born overseas are the same as in Australian-born residents (24.5%), cancer profiles varied by country of birth, with a large proportion of primary liver cancers occurring in overseas-born people (46%).¹³

Further evidence of the impact of hepatitis B-related liver disease comes from a New South Wales linkage study. Notifications of hepatitis B were linked to the New South Wales Cancer Registry and National Death Index. People with hepatitis B had a 40% to 90% increased risk of mortality compared to age- and gender-matched New South Wales population. Although many deaths were unrelated to liver disease, the risks of total liver disease-related and liver cancer-related mortality were 12 and 33 times higher, respectively, than those for the background population.¹⁴

Currently, it is estimated that 2% of the total number of people with chronic hepatitis B, and only a small minority of people who would be recommended for treatment, receive antiviral therapy with up to 36,000 being eligible for therapy.¹⁵

Prevention of hepatitis B infection

The major response to preventing hepatitis B transmission includes securing the blood supply and the funding and implementation of the hepatitis B immunisation program.

Chronic hepatitis B can be prevented with a safe and effective vaccine which became available in 1982.¹⁶ Hepatitis B immunisation of at-risk infants began in 1987; the adolescent dose became available in 1998; the universal infant dose commenced in May 2000 (available in Northern Territory since 1990), and the adolescent catch-up program since 2002.¹⁷ Hepatitis B vaccine is funded through the Immunise Australia Program - a federal, state and territory initiative which seeks to increase national immunisation rates.

The Australian Immunisation Handbook¹⁸ recommends hepatitis B immunisation for the following groups

- infants and young children
- adolescents aged between 10 and 13 years
- household contacts (other than sexual partners) of people with acute and chronic hepatitis B
- sexual contacts of people with acute and chronic hepatitis B
- people on haemodialysis, individuals with HIV and other adults with weakened immune systems
- people who inject drugs
- recipients of certain blood products
- individuals with chronic liver disease and/or hepatitis C
- residents and staff of facilities for persons with intellectual disability
- individuals adopting children from overseas

- liver transplant recipients
- inmates and staff from long-term correctional facilities
- health care workers, dentists, embalmers, tattooists and body-piercers
- others at risk including
 - police, members of the armed services and emergency services staff
 - long term travellers to regions with high endemicity
 - staff of child day-care centres
 - people playing contact sport

The Australian Government funds the distribution and administration of the infant schedule of hepatitis B vaccine. According to the Australian Immunisation Registry by 30th June 2007, 94.5% of Australian infants aged 12 to 15 months had been vaccinated against hepatitis B. Adolescents in Year 7 or aged between 11 and 13 years receive a two dose course of adult hepatitis B vaccine given 4 to 6 months apart. In 2005, 74% of adolescents enrolled in Victorian schools had completed the course of hepatitis B vaccine. The need to identify hepatitis B disease burden, and that the impact of vaccination on hepatitis B disease burden in Australia is 'less clear' compared with other countries with longer standing vaccination policies, was noted by Williams.¹⁹

Communicable Diseases Australia note an 81% reduction between 2001 and 2005 in hepatitis B incident notifications in the 15-19 year age group, and 58% among the 20-29 year age group which it suggests occurred due to increased adolescent vaccine coverage.²⁰

Significant variations exist between Australian jurisdictions in the availability of *funded* hepatitis B vaccination to people considered at high risk of exposure to hepatitis B infection, and for whom vaccination is *recommended*. This lack of consistency between jurisdictions also relates to the level of publicly available information about access to funded hepatitis B vaccination. In some jurisdictions, the only information available from departmental websites about the hepatitis B vaccination program is for the Immunise Australia Program, with detail on specific state or territory initiatives either unavailable or unfunded.

The majority of Australians with hepatitis B were born in countries where health service provision, including access to vaccination programs is limited, and where many have spent extended periods in refugee camps. Australia accepts approximately 110,000 migrants (including 13,000 refugees) each year. The Department of Immigration and Multicultural Affairs note that 'Australian health authorities consider that the risk of newly arrived migrants transmitting hepatitis is low' and that:

'All applicants for permanent visas, including the main applicant, spouse and any dependants, must be assessed against the health requirement... Examining doctors ... may also ask any applicant to undergo tests for hepatitis where they consider it necessary'.²¹

Hepatitis B surface antigen blood tests are ordered for

- pregnant women
- a child for adoption by Australian resident
- unaccompanied minor refugee child
- people who have been in immigration or other detention facilities, whether in Australia or overseas
- temporary entrants intending to work in Australia as a doctor, nurse or dentist
- people with clinical indication

Hepatitis B testing appears to be performed based on the characteristics of the individual, rather than the requirements of the visa they are applying for. The impact of a positive hepatitis test are noted in the DIMA Fact Sheet 22:

‘Where a test proves positive for hepatitis, the application will not necessarily be rejected although further tests may be required. In most cases the applicant will be asked to give an undertaking to report to the Health Undertaking Service for referral to State or Territory health authorities on arrival in Australia’.

Awareness campaigns to improve immunisation participation rates and to increase hepatitis B treatment access occur in several Asian countries. These include a ‘Hepatitis B Awareness Day’ in Malaysia; mass education campaigns in Taiwan; public education campaigns through primary health care physicians, and a ‘Liver Day’ held in Korea.²²

Treatment of chronic hepatitis B

The goals of hepatitis B treatment are to eliminate or permanently suppress viral replication; reduce the risk of progressing to advanced liver disease, and the development of complications such as liver failure or liver cancer. The two major drug classes used in treatment are the interferons and the nucleotide (adefovir) and nucleoside analogues (entecovir and lamivudine).

Both drug classes are able to suppress hepatitis B virus replication, reduce liver inflammation, and reduce the risk of liver disease progression, but generally less than 5% of people can fully ‘control’ their hepatitis B infection, even with treatment.

Currently, treatment for hepatitis B involves the use of a single agent (monotherapy), either an interferon or a nucleoside or nucleotide analogue. Monotherapy has been associated with sub-optimal responses and high levels of drug resistance (particularly with ongoing nucleoside and nucleotide therapy). These limitations, plus the development of new antiviral agents, provide the rationale for adopting new therapeutic strategies, especially combination therapy which has clearly been shown to be superior in the management of HIV and hepatitis C infections. Early combination-therapy studies in hepatitis B have indicated reduced rates of drug resistance, providing optimism for the potential of combination strategies to control hepatitis B,²³ and calls have been made in Australia to introduce funded combination therapy.²⁴

Pre-treatment liver biopsy is required for access to therapies through the Australian Government Highly Specialised Drug S100 Scheme for the treatment of chronic hepatitis B. Licensed therapies for hepatitis B treatment are interferon alfa and pegylated interferon alfa-2a, and also lamivudine, adefovir, and entecavir. The main side effect of antiviral medication (lamivudine, adefovir and entecavir) is the development of mutations in the hepatitis B virus, called antiviral resistance.

Blood tests are used to monitor signs of antiviral resistance. If signs of resistance such as elevated liver enzymes and high levels of hepatitis B virus DNA in the blood occur, the antiviral medication may be altered. The HBV DNA test is the most significant test needed to diagnose antiviral resistance and is expected to be funded for use by the Australian Government from November 2007.

Monitoring for the response to chronic hepatitis B treatment consists of regular liver function tests (every 3 months) and hepatitis B serological tests (every 3 to 6 months, particularly in people who are HBeAg positive). Monitoring of virological response through regular (every 3 months) viral load (HBV DNA) assessment is recommended.

Management of people with chronic hepatitis B

There is a dearth of information, knowledge or insight into the non-clinical aspects of living with chronic hepatitis B.

A 2007 study on quality of life for people with hepatitis B in the United States note a lower score on the SF-36, a quality of life measuring tool, than controls and that guidelines for management of hepatitis B do not 'routinely consider' quality of life when making treatment decisions.²⁵ The authors found that 'patients with non-cirrhotic hepatitis B have substantial psycho-social decrements in quality of life'; that quality of life is better in patients achieving a viral response to treatment, and treatment 'may have' significant short-term benefits for psychosocial health.

Barriers to hepatitis B treatment have been identified as the lack of education and awareness of hepatitis B disease, which in the broader Asian-Pacific region also includes treatment costs, social stigma and fear of discrimination.²⁶ Lack of disease awareness has been associated with poor patient adherence to therapy, and barriers to treatment include fear of discrimination, fear of loss of employment or insurance, failure to perceive benefits of therapy and fear of discomfort.²⁷ Some Asian countries have developed draconian responses to hepatitis B and widespread government generated discrimination is reported in China.²⁸

Information deficits of patients with chronic hepatitis B have been reported, with people with hepatitis B less informed of issues on viral load and problems with work than people with hepatitis C.²⁹ A study of 301 patients on anti-viral therapy in the United States found 31% of patients knew the names of hepatitis B related tests, although only half knew what the tests measured; one third had not discussed treatment goals, while 89% thought that this should occur; 51% felt involved in treatment decisions, and 54% were unsure why the drugs they were taking had been chosen. This study also showed a lack of understanding of how hepatitis B was transmitted with 36% of respondents believing that hepatitis B could be transmitted by sharing utensils.³⁰

Research with primary care physicians in Singapore identified a series of barriers to the management of hepatitis B infection including poor compliance with disease monitoring; apathy; stigmatisation; confusion between hepatitis B and other liver related viruses; passive attitude of the doctors; lack of recall system by services, and an absence of local epidemiological data.³¹

Economic burden of hepatitis B

Little is known of the economic burden of hepatitis B in Australia. A retrospective analysis of 149 patients with chronic hepatitis B with six disease states (non-cirrhotic chronic hepatitis B, decompensated cirrhosis, hepatocellular carcinoma, liver transplantation in year 1 and in subsequent post-transplantation years) was conducted and the average annual costs per patient were calculated. This study concluded that the costs of managing patients with hepatitis B varied significantly between the non-cirrhotic chronic hepatitis B and the other disease states and that the annual costs of managing a patient with non-cirrhotic chronic hepatitis B in 2001 were \$1,233 compared to \$144,392 for a patient who has a liver transplant.³²

Responding to chronic hepatitis B

No comprehensive coordinated approach exists which specifically addresses the needs of people with chronic hepatitis B in Australia. The major public health responses to hepatitis B include securing the safety of the blood supply since the early 1970s; the funding and implementation of the hepatitis B immunisation program, and the provision of treatment through the Pharmaceutical Benefits Scheme.

Hepatitis B is noted within several national health strategies. The *National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy 2005-08* acknowledges a 'safe, effective and inexpensive vaccine' for hepatitis B; a reduction by two-thirds of new diagnoses of hepatitis B between 1999 and 2003, with this rate remaining more than double that of the non-Indigenous population. Hepatitis B is acknowledged in the *National HIV/AIDS Strategy 2005-08* which notes the poorer health outcomes of people co-infected with HIV and hepatitis B and/or hepatitis C, and supports the promotion of a policy for vaccination of people diagnosed with HIV/AIDS and/or hepatitis C. The *National Sexually Transmissible Infections Strategy 2005-08* notes that hepatitis B is a vaccine preventable infection, while the *National Hepatitis C Strategy 2005-08* encourages hepatitis B vaccination for people 'especially in custodial settings'.

The ACT-HBV Australia and New Zealand Local Chapter were responsible for the development of *Hepatitis B in Australia: Responding to a Diverse Epidemic* (2007). This document sought 'to raise public awareness of hepatitis B, develop advocacy for a national strategy, and provide a platform for developing a concerted public health response to this increasingly important epidemic.'

Hepatitis Australia, the peak non-government organisation consisting of the state and territory based hepatitis councils released a position paper describing the current public health response to hepatitis B as 'clearly limited and less than optimal'.³³ The organisation called for the development of a comprehensive

national hepatitis B strategy; development of health maintenance and support resources for people affected by hepatitis B, and for infrastructure to represent people living with hepatitis B.

The (then) Hepatitis C Council of WA was funded by the Health Department of Western Australia in 1997 'to investigate the needs of those people with hepatitis B'.³⁴ The organisational context of this assessment was the council moving from a hepatitis C specific organisation to broadening their mandate to encompass other forms of viral hepatitis. The findings of the assessment noted a need to encompass diversity in providing services and the development of resources for people with hepatitis B. The report made a series of recommendations focussing on the role of the council in hepatitis B; the need for resources, and education and training for service providers.

In mid-2007, the Cancer Council NSW commenced a pilot project developed as a result of the findings of *Cancer Incidence in New South Wales Migrants 1991 to 2001*.³⁵ This report showed that while cancer incidence rates in people born overseas were the same as in Australian-born residents (24.5%), cancer profiles varied by country of birth, with a large proportion of primary liver cancers occurring in overseas-born people (46%). The project seeks to increase detection of hepatitis B infection; ensure regular follow-up of people with chronic hepatitis B and vaccination for those not immune, and to facilitate referral for hepatitis treatment. The program will screen people at risk of liver cancer and aim to increase the proportion of people whose disease is diagnosed early - at a stage where it may be cured through surgical intervention. The pilot project is being implemented in south-west Sydney in 2008-09 as a Cancer Council-led collaboration between hospital clinicians, general practitioners, researchers and community organisations representing the relevant communities.

Internationally, coordinated responses to hepatitis B generally focus on the implementation of vaccination programs. One exception was the development of *Hepatitis B: revealing a silent killer*, where a series of challenges were noted in a workshop to 'propose a way forward to address hepatitis B in European policy' for the European Parliament.³⁶ These challenges were a low awareness about hepatitis B among individuals and public health authorities; stigma; under-diagnosing and treating of hepatitis B; limited treatment options; a poor evidence base, and the need for active targeting of 'at risk' groups.

The workshop prioritised solutions including

- hepatitis B policy development
- better information to patients about risks, prevention and treatment options
- developing communication about hepatitis B to reduce stigma
- sharing best practice to improve treatment outcomes
- better surveillance systems and data
- stronger evidence base particularly on prevalence and incidence; treatment failure and viral resistance; improving prevention, and raising awareness
- improved vaccination programs
- improved access to care and improving management of disease
- targeted programs for immigrants and health care workers

Communities most affected by chronic hepatitis B

People with, or at risk of, chronic hepatitis B infection come from a diverse cross-section of ethnic and social backgrounds. Hepatitis B infection exists in communities that are often marginalised from generalist health services. This diversity presents specific challenges to implementing a comprehensive and inclusive response to hepatitis B, particularly in developing health promotion options and models for patient management.

People born in Asia and the Pacific Islands

Ethnicity is strongly associated with almost every measure of health and disease, and low socio-economic status. Social exclusion and isolation affect the health status of ethnic groups, some of whom are also coping with prior hardships. Language difficulties and cultural health beliefs and practices influence health literacy, including access to health services.

There are high rates of chronic hepatitis B in many countries within the Asia-Pacific region because of high levels of mother to child and early childhood transmission. Most people with chronic hepatitis B in Australia were born in Asia and the Pacific Islands.³⁷

An assessment of hepatitis B knowledge and prevalence in Melbourne, Australia found 9 of 95 Laotian, and 8 of 234 Cambodian immigrants or refugees had chronic hepatitis B of whom, 79% were unaware of their infection.³⁸ The participants in this survey had been resettled for between 12-14 years, and while diagnosis rates were low, 56% of Laotian and 96% of Cambodian people had contact with a health care provider (most frequently a general practitioner) in the last 12 months.

In the United States, hepatitis B knowledge among Vietnamese immigrants has been found to be generally poor; one study showed that only 28% had ever heard of hepatitis B virus vaccination³⁹, while a study of immigrant Vietnamese adolescents in the United States found knowledge of hepatitis B, including prevention, was low.⁴⁰ Similar findings are found in some Chinese communities in the United States with vaccination not understood as a primary prevention strategy for hepatitis.⁴¹

People born in other hepatitis B-endemic regions

People born in other hepatitis B-endemic regions have a higher rate of hepatitis B infection than in the general population. These regions include Africa, the Middle East, and the Mediterranean region. People from the Mediterranean region (predominantly Italy, Greece, and Malta) constituted 16% of a Melbourne liver clinic population with chronic hepatitis B.⁴² Martin and Mak note the proportion of African migrants accessing the Migrant Health Unit in Western Australia rose from 43% in 2002 to 79% in 2003 and 2004, and higher chronic hepatitis B infection rates in people from the African sub-Saharan (6.4%); southeast Asia (6.5%) and north Africa (6.8%).⁴³ This geographical variation in chronic hepatitis B prevalence is reflected among African refugees in Melbourne with higher rates among people from western rather than eastern Africa.⁴⁴

Indigenous Australians

Indigenous communities experience a huge burden of ill health and disease, requiring health services to respond to multiple and competing priorities. Indigenous communities live within a context of greater morbidity and mortality than experienced by the broader Australian population, including high death rates in early to middle adulthood. Life expectancy at birth for an Indigenous person is 59.4 years for men and 64.8 years for women, in comparison to 77.8 years for men and 82.8 years for women in the non-Indigenous community.

Indigenous Australians constitute an estimated 16% of people in Australia who live with chronic hepatitis B; this is in spite of these communities representing 2% of the Australian population. The prevalence of chronic hepatitis B among Indigenous Australians varies according to place of residence, with estimates varying from 2% for urban Indigenous populations to 8% for rural Indigenous populations with remote Aboriginal communities likely to have higher prevalence rates and higher rates of liver cancer.⁴⁵ A study of hepatitis B prevalence in a maternal hospital in Darwin in 2003 found an overall prevalence of hepatitis B surface antigen in Indigenous pregnant women of 4.07% and non-indigenous women of 1.16%.⁴⁶

Differences have been identified between Indigenous 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 Indigenous people, versus 15 in 2004 and 16 in 2005 per 100,000 in the non-indigenous population.⁴⁷ Significantly higher rates were found among Indigenous people in remote areas (153 per 100,000) compared to rural (24 per 100,000) and metropolitan areas (47.5 per 100,000).⁴⁸ Death rates for all causes of chronic liver disease and cirrhosis between 1991 and 1995 were 4 and 5.5 times higher for Indigenous men and women compared to the general Australian population.⁴⁹

Hepatitis B immunisation, including universal infant vaccination, was implemented in many Indigenous Australian communities from the early 1990s. 'Catch-up' hepatitis B vaccination was implemented for Indigenous children and adolescents in the late 1990s. A survey of vaccination status among teenagers in one Queensland community showed only 44% were fully vaccinated, with more than 90% of the incompletely vaccinated teenagers being exposed to hepatitis B, and 26% being chronically infected.⁵⁰

The *National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy 2005-08* identifies access to local primary health care as the foundation of a functioning health care system. Access to hepatitis B treatment and care services is limited, partly because of poor overall access to primary and tertiary health care services in many Indigenous communities.

People who inject drugs

An estimated 100,000 Australians regularly inject drugs, with an additional 175,000 people involved in occasional injecting without dependence or social isolation.⁵¹ It is well documented that people who inject drugs experience discrimination particularly within health care settings.⁵² This results in poor levels of general health, which may be compounded by other social problems such as poverty, unemployment, and poor access to housing, welfare, and other support services. Higher rates of hepatitis B and hepatitis C has been found

among homeless people than in the broader community.⁵³ These issues affect the capacity or willingness of people who inject drugs to prioritise health issues, particularly with reference to conditions such as chronic viral hepatitis, in which the initial impact is generally silent and where the potential longer-term disease complications have little immediate relevance within the broader social context.

Risk factors for hepatitis B exposure among people who inject include older age, duration and frequency of injecting drug use, sharing of needles and syringes and incarceration.⁵⁴ The prevalence of chronic hepatitis B among people who inject drugs is approximately 2% with Maher finding 2.7% surface antigen positive among people who inject in south-western Sydney, with a further 46% of the sample being susceptible to infection.⁵⁵ The low rate of chronic hepatitis B among people who inject relates to the high proportion of adolescent and adult infection - a population who more likely to clear the virus than people infected in infancy.

Levels of knowledge about hepatitis B are poor among people who inject drugs and people who inject are often unaware of hepatitis B vaccination⁵⁶ and/or do not complete vaccinations.⁵⁷ Misconceptions regarding infection status are also very common. Despite the high risk of hepatitis B exposure among people who inject drugs, only a minority have been vaccinated for hepatitis B. A survey of drug and alcohol agencies found that less than half of the sample offered testing and vaccination.⁵⁸ Poor access to primary health care services among people who inject drugs, as well as social marginalisation, often make completion of a 3-injection vaccination course over a 6-month period, difficult.

Hepatitis B and hepatitis C share common transmission routes and most people who inject drugs who have chronic hepatitis B will be co-infected with hepatitis C.⁵⁹ Co-infection with hepatitis B and hepatitis C increases the risk of liver disease progression, including progression to cirrhosis and liver cancer, and makes clinical management of both viruses more difficult.

Men who have sex with men

The prevalence of chronic hepatitis B among men who have sex with men is approximately 2%, although as with people who inject drugs, rates of hepatitis B exposure in this population are considerably higher than in the broader community. A study conducted in Sydney in 2001 found among men who have sex with men without HIV, approximately 20% had evidence of prior hepatitis B exposure. Factors associated with hepatitis B infection are the number of sexual partners, a history of other sexually transmissible infections, and older age.⁶⁰

Hepatitis B vaccination uptake rates among men who have sex with men have improved, but a large proportion of young men remain susceptible to hepatitis B infection. The risk of transmission of hepatitis B and HIV among men who engage in unprotected sex means that the rates of hepatitis B and HIV co-infection are higher. Co-infection with hepatitis B and HIV increases the risk of liver disease progression, particularly for people with advanced immune deficiency.

People in custodial settings

Chronic hepatitis B prevalence among Australian prison inmates has been described between 1.8%⁶¹ and 3.2%⁶², although rates of exposure to hepatitis B infection are 30% to 40%. More recent research finds similar figures (3%) with

slight jurisdictional variations in prevalence.⁶³ The higher hepatitis B prevalence in custodial settings relates to the high proportion of people with a history of injecting drugs, and the high proportion of Indigenous people within the prison population. Indigenous prisoners have a particularly high rate of chronic hepatitis B, with levels above 10% in one New South Wales study⁶⁴. Some jurisdictions offer hepatitis B screening and vaccination for people in custodial settings, but this is not a universal practice.

Assessment Findings

The Ottawa Charter for Health Promotion assisted in providing a structure for describing the findings of the needs assessment. The charter has been used by the Australian and other government in framing national strategic responses to HIV/AIDS, sexually transmitted infections and hepatitis C. The charter defines health promotion as a process of enabling people to increase control over and improve their health, and recognises the political, economic, social, cultural, environmental, behavioural and biological determinants of health.

The findings of this assessment are organised into three distinct sections

1. the experience of living with hepatitis B
2. health service responses to hepatitis B
3. public health responses to hepatitis B

A series of priorities for action resulting from the consultations have been developed and are included after the findings.

The act of the researchers asking service providers about hepatitis B can result in focussing on the deficits in the response. However concern should be ameliorated by the consistency in responses to various issues from a range of professional and personal perspectives. While there was consistency in the responses, this assessment also acknowledges where conflict occurred between differing perspectives.

Data were collected from all interviews in a qualitative form and progressively established key issues, concepts and themes. All participants in the assessment were assured of confidentiality. In reporting their comments, and to assist in clarity, quotes from participants with professional responsibilities have been grouped into four, sometimes overlapping, classes

- Community workers - people from peer-based injecting drug user groups; hepatitis councils, and people working with CALD communities including refugee support services
- Health workers - people providing non-clinical health services through community and government based organisations including health and social researchers
- Program officers - people working in government instrumentalities including communicable diseases, multicultural or Indigenous health units/branches or providing advice to government through advisory structures
- Clinicians - specialists, including gastroenterologists, infectious disease physicians, hepatologists, hepatology nurse consultants, drug and alcohol clinicians, and general practitioners

Section 1 - Chronic hepatitis B – the lived experience

Hepatitis B as a public health issue is largely described using a medical or prevention framework and the lived experience of people who are infected with hepatitis B has rarely been investigated. This section looks at the lived experience of chronic hepatitis B and draws on a series of brief interviews with people with chronic hepatitis B. The major issues identified from interviews with people with hepatitis B included the circumstances in which people were diagnosed with hepatitis B; how people manage their hepatitis B infection and how they addressed disclosure.

Testing and diagnosis

Hepatitis B testing occurs in a range of settings and within differing life contexts. For people with hepatitis B interviewed for this assessment, testing occurred as a result of a family member or friend being diagnosed with hepatitis B; employers instigating testing; tested upon entry to drug rehabilitation, or being tested as one part of the immigration process.

None of the people with hepatitis B interviewed as part of this assessment reported receiving formal or informal pre- or post-test counselling. Several people were unaware that they had provided consent for testing - *I didn't ask for it, just through a normal blood test.*

One respondent noted that he was tested for a range of illnesses on entry to rehabilitation centre and that he couldn't *remember the amount of consent that I gave.*

For several of the people with hepatitis B, testing occurred within a context of whole families being tested:

When I was in high school, dad found out he had hep B through the GP and then the GP got the whole family tested.

I found out from the doctor because my mother has hepatitis B and passed [it] down to us, and the family doctor [suggested the family] have [a] hepatitis B blood test ... then we all found out we have hepatitis B ... yes, the whole family.

National responses to other blood borne viruses such as hepatitis C and HIV have included the development of pre- and post-test discussion protocols. These protocols ensure that standardised and accurate information is provided to people upon diagnosis. One impact of the lack of pre - or post-test counselling or discussion meant that finding that they were chronically infected with hepatitis B was described by several people as 'shocking':

She [the doctor] called me into the office and she said to me 'sorry but you got hep B' and I was in shock because from where did this one come?

She [the doctor] said don't worry, just yourself look after [yourself], so eat, sleep, so I ... just don't know what to do, just miserable you could say because I'm just wondering why I got it.

Little information about hepatitis B or its impact was provided to people at the point of diagnosis:

They didn't give me any information ... all I know is that it was hepatitis B.

Nothing ... I'm sick and I'm waiting [to see the specialist].

They just told me you have hepatitis, and you try to stop the drink the beer, or eat something like diet something.

Some people had a limited understanding of hepatitis B when they were diagnosed - *only one thing I know was that there was no medicine.*

Several of the respondents reported confusion between chronic hepatitis B infection and cancer - *I think it was like a cancer or something.*

A lot of people believe that once you have hepatitis B you'll end up with liver cancer.

For others, the diagnosis triggered fears for the future - *how long will I live? Will I survive? Will I be able to have kids?*

When I went to see the family doctor and she told me that I got it, it was shocking, because I don't really fully understand what hepatitis B is but I know that sometimes it can lead to serious problems.

I went to see the family doctor and she told me that I got it ... it just feels really shocking and [I'm] really a bit stressed because I don't know what will happen in the future.

How hepatitis B is affecting my body and [what's] it going to cause in the future?

One person with hepatitis B after being diagnosed by their general practitioner remembered an additional surprise in being contacted by health department contact tracers - *I had no idea that I was going to get a call from somebody asking about my sexual behaviours.*

When relevant and/or accurate information is not provided at the point of diagnosis, people sought information from within their communities:

When they say hepatitis, because I wasn't sure what does it mean hepatitis B ... I asked some other people and then they say this means this kind of thing in our language we say ... it means that this skin is yellow.

People who were diagnosed with hepatitis B in their country of origin reflected the endemic nature of hepatitis B within southeast Asia:

I got a test in Cambodia and the doctor told me I have hep B, but in Cambodia it's like normal, they don't care what happens you know.

As noted before, receiving a positive diagnosis for chronic hepatitis B can be shocking. One person reported they couldn't remember what information about hepatitis B had been provided to them when they were diagnosed - *nothing that I remembered, if there was anything it didn't stick.*

One health worker reported their experience in providing a diagnosis to a patient which reflected the lack of information provision and other resources at the point of diagnosis:

He was an intelligent, educated young man but because the GP hadn't told him or started that slow education counselling process, by the time he got to me it was a huge catastrophe, he was going to die, his wife was going to leave him, I didn't have any information to give him ... we need to situate the disease in all the cultural issues.

Evidence of inadequate information and missed opportunities for reducing transmission both by people with hepatitis B and medical professionals were noted by one respondent whose child was infected with hepatitis B at birth and is now chronically infected:

My daughter, she's only 2½, me and my husband, he suffers from hepatitis B ... that's no good at all ... we just found out a year ago that she's got hepatitis B, she was born here.

Other people reported being angry with medical professionals and blamed lack of education of their general practitioner about immunisation for their infection:

When I came to Australia about 12 years ago, we got our first injection to avoiding any hepatitis type of viruses and the needle [immunisation] only last 5 years time, but our GP didn't tell us. If the GP had told us at the 1st stage, I might just continued the needling, and possibly it [transmission] won't have happened. But she didn't tell us the right thing, and I had the chance of getting hepatitis B.

For many people interviewed, hepatitis B was part of the inter-generational family dynamics – *my mum had it, and she probably passed it on.*

I've lived with hep B all my life, I live with my mom, and so I do contact with hepatitis B ... my brother has hep B.

My sister, my father, my wife, my mother ... my father, he's 80, he carry long time.

Sometimes the familial links challenged the view of hepatitis B as a virus - *the whole family have hep B except for my father ... maybe it's a blood thing.*

The inter-generational nature of hepatitis B infection caused distress for many of the people interviewed, and the implications of them transmitting the virus within their family - *I was absolutely dead when they told me [that her family may have been infected].*

Being Asian in and of itself was seen as a risk factor for hepatitis B:

I really want to find out but is it because of Asia? I don't know, I know most people from Asia have got it.

I'm from China, so most of the Chinese people have got it.

In Asian people plenty people, maybe 20, 40 percent have hep B.

In Cambodia it's like its normal ... not everyone but probably about 50%.

Hepatitis B was associated by many people with sanitation which reflected misunderstandings of transmission risks:

I think I was infected in China, and we used to share foods, drinks, so I think that's how I got infected.

I don't know, you know the conditions in Asia, those parts of the world aren't very clean and are easy to get infection it just happen it very common.

Up to 5% of people with chronic hepatitis B in Australia are men who have sex with men, some of whom were also infected with HIV. For one person, also infected with HIV, being diagnosed with hepatitis B was an additional psychological challenge which was dealt with by denial:

I thought right, fuck, ok, let's put all of that in this compartment over here called the too hard basket and pretend nothing is happening.

Several interviewees were fatalistic about having hepatitis B - *I've got it ... there's nothing much I can do, it's up to the virus.*

Managing hepatitis B

The provision of pre- and post-test information at the point of diagnosis is important in ensuring that people understand the disease and are able to respond effectively. Several people noted that the lack of information at the point of diagnosis had a significant impact on their behaviour which resulted in poorer health outcomes:

I don't think it bothered me very much at the time ... I didn't know that hepatitis B could be problematic ... I don't think that was explained to me.

Now that I know it damaged my liver yeah, I would have been a bit better off if I knew more ... if they told me a few years ago that I wasn't really meant to drink alcohol ... I would have cut down on it.

One respondent who had been diagnosed for several years, found his general practitioner not useful in helping to self-monitoring his health:

I told the doctor that I had an e-antigen test, and he goes 'the result?' and I go 'I don't know, it's not active' or something and it was left there ... he hasn't followed [it] up.

One person, chronically infected with hepatitis B, and who had not seen a specialist got the impression from his diagnosing general practitioner, that *it's not something to be worried about ... I don't know where I'm at.*

While it was reported that little information was provided to people at diagnosis, several respondents reported reducing alcohol consumption and undertaking lifestyle changes:

After I found out I had hepatitis B, I quit drinking after they told me drinking could make it really worse for the liver ... I get a bit sick of alcohol anyway ... It makes it better for life anyway.

No drink ... little bit drinking, eat less fat, eat less and try to lose the weight, exercise, eat more vegetables.

I keep good health, I exercise, I don't drink alcohol ... before I drink with buddies, but now I drink one or 2 bottles.

Evidence of lack of or mis-information about hepatitis B was evident in several interviews with people with hepatitis B. One person who had been diagnosed for several years noted - *I heard about people killed by hep B and C but I'm just like at the beginning and I'm a carrier.*

Being identified as a 'carrier' was noted by a couple of people as being an encouraging sign - *I had hep B not much just a little bit, just carrier and no treatment.*

I don't think [my mother] has it - I think she's a carrier or something.

Another person noted that they weren't being treated for hepatitis B because *not yet ...just a carrier.*

Several people interviewed were proactive in finding out information about hepatitis B which sometimes meant finding out about traditional methods of dealing with liver disease:

I study everything about health ... I open the internet, I look for health, I worry about, I nearly 60 years old, I need to learn about food that can help the liver... I try artichoke - here, they like food; in Vietnam they like the tea. That helps the liver very much ... I have friends that send me information that helps reduce cancer, through email.

The familial nature of hepatitis B meant that different people within the family were managing hepatitis B in different ways. One respondent talked about his brothers:

[He] died of hepatitis B - drank too much, while another [brother] has spent about \$10,000 on Chinese traditional therapies and is monitoring [his own progress].

While some were proactive in seeking information, denial and fatalism also played a part in one person's response:

I went onto the internet, but didn't read much about it because I think I was a bit scared to know in more detail, 'cause ... what will happen to me in the future will happen.

How people emotionally respond is important in terms of their self-management. For one person:

[Hepatitis B] ruined my life ... everything that I worked hard for, all the potential that I had and you know I fucked up, and then you get into all that self loathing, and the shame and the stigma and this is all about my low self-esteem.

The chronic nature of hepatitis B treatment for many people was reflected by one man who had successfully incorporated hepatitis B treatment into his life:

The only thing is that I'm sick of taking the tablets every day, now I'm used to it, if I don't take the tablets I'm thinking I forgot something.

Several people described lengthy gaps in terms of monitoring their hepatitis B. How people interpreted various aspects of hepatitis B serology and the impact this had on monitoring was noted by one man:

I thought it was only a weak sign so I didn't even bother about [treatment] ... so I didn't get regular blood tests or anything.

Another person diagnosed in 2001 with chronic hepatitis B had not been monitored except for an e-antigen test in 2005 and was not confident of the skills of his general practitioner in relation to hepatitis B:

I think he may know the core antibody, surface antigen but the e-antigen test, I'm not sure if he sort of knows, he hasn't helped me understand it at all ... you'd hope he does.

This respondent had only recently found out from a colleague that treatment for hepatitis B was available.

One person diagnosed when they were 17 years of age noted that growing older and having children provided the motivation for being proactive in addressing health issues:

When you're young and you ignore your health, it's really common for young people ... but I have family of my own, and I got my own children and I started to look at it a bit more ... and I just follow what the doctors suggests that I do

Co-infection with HIV and hepatitis B is complex. One person noted:

Your HIV drugs fuck up your liver which cause hepatitis B flares ... and you just get into this cycle, and then your hepatitis B fucks up your liver which means that you can't process your HIV drugs.

Disclosing hepatitis B

Hepatitis B is seen as a shameful thing within some communities, and can highlight traditional ways of dealing with vulnerability:

If you come from a different cultural background, the way you avoid disease is through exclusion, and so if that works with some things, then they [do the same with hepatitis] ... so if you are in an intimate relationship with somebody then that can cause problems. (Community Worker)

Participants in the interviews were asked whether they disclosed to others that they were infected with hepatitis B. For respondent, disclosure wasn't an issue - *most of my friends I've told once.*

Some respondents talked about complex rules about disclosure:

It's about being almost street-smart with who takes information on.

I might be more forthcoming with [people who knew that I had injected drugs] while other people who knew I was gay I would disclose HIV infection ... the rules always changed depending on who I was with.

The complexity was complicated by family members living overseas:

I told my brother, but not my mom ... I don't want them to be sad for me, I don't want them to worry ... she's in Pakistan.

The inter-generational nature of hepatitis B transmission for one person meant that there was no shame associated with infection, and that for them disclosing their hepatitis B status was straightforward.

I didn't get it from a sexually transmitted disease, because I got it from my dad, I feel comfortable about telling people how I got it ... I had nothing to hide because it was given to me from birth.

The fear of rejection concerned several people:

I don't want to tell any of my friends because I'm afraid they might just get away from me, I don't think it is a good thing to tell, it's not like I win tattslotto.

I didn't let my brother know because he's only 10 ... I don't want him to ... go to school and tell anyone because kids are kids. It's not a big deal but if he says that his sister's got hepatitis B then all the other children might [think they can get infected by the brother] ... I don't want to change his life.

I don't feel comfy telling people that I have hepatitis B ... people will stay away from me.

One person had very clear rules about disclosure:

If they don't ask I'm not telling them.

The reaction to a person's initial disclosure of being infected was noted as being important for one person:

For me it's not shameful because the people I have told have been supportive. I think if I had told the first person and they weren't supportive I wouldn't have continued it.

Not disclosing meant that several of the people interviewed did not know other people with hepatitis B:

I don't know many people with hepatitis B - it's not something that you put on the table.

The impact of the shame associated with hepatitis B was noted by one community worker:

People don't want to tell their loved ones ... about what's going on ... they become very scared.

One person with hepatitis B noted a reduction in their experience of shame after finding more information about hepatitis B. For them this additional information meant:

I wasn't bad, I was just in the wrong place and the wrong time ... shit happens.

Section 2 - Chronic hepatitis B – the health service experience

The complexity of the hepatitis B virus and its interaction with specific populations most at risk of chronic infection provides challenges to the capacity of the health system to effectively address the needs of populations most at risk of chronic hepatitis B. This section of the report discusses the relationship between health service provision, hepatitis B and people with chronic hepatitis B by looking at health service access; information provision by health services; treatment; general practice; referral and shared care and workforce development.

Health service access

Available epidemiological information shows the majority of people with chronic hepatitis B in Australia come from CALD communities. The communities most affected by chronic hepatitis B in Australia have changed significantly over the past few decades and will continue to change:

In the last 5 to 7 years we were starting to see a dramatic change in the number of Asians, and in the last two years, quite a lot of Africans coming. (Community Worker)

These changes of specific communities affected by hepatitis B challenges health service provision - *five years ago we weren't seeing such high rates of disease and it's something that probably won't go away. (Clinician)*

One clinician noted the significant delay between communities arriving in Australia and the capacity of the health system to respond effectively to the changing community profile.

I think the public system has really got to up its game, take on the Asians more and more, which they're doing better because they've been around for the last 30-40 years. Then you get the African side of it tied up as well ... [and] whether the African interpreter services are up to dealing with African populations.

Much of the information gained throughout the needs assessment, particularly from clinicians, looked at the delivery of health services to populations whose understanding of health issues is often limited and/or not based on western medicine. This has significant implications for the management of people with chronic hepatitis B. The majority of clinicians noted that the different understanding of people from CALD communities related to fundamental concepts of western medicine:

They really have very little understanding of their disease ... partly because their background concept of health and liver, and what it does, is minimal. (Clinician)

These different perspectives also included broader understandings of the liver and concepts of health - *they just don't understand viral wording at all. (Clinician)*

Some of the health and community clinics have clients from a broad range of CALD communities. This breadth of clientele meant lacking adequate resources to

respond not only in the appropriate language but also in a culturally appropriate manner. One community worker noted:

The service I coordinate have currently over 50 different countries of origin in our client group.

Another community worker noted the breadth of their client group and the implications of this for the provision of information to their clients.

The majority of our patients are from China, southeast Asia, we have quite a few from the Balkan states ... some from Italy and in and around the Mediterranean ... it's not about translating word for word what has been written in English ... but it's accommodating for cultural issues as well.

As with many people in the broader Australian community, people with hepatitis B from CALD backgrounds have an expectation that hepatitis B can be 'cured' by western medicine. This challenges perspectives of western medicine being able to cure viruses - *getting their head around that there is no cure for this condition.* (Community Worker)

The processes used in hospitals, such as access and monitoring, were noted as confusing for some populations. One health worker reported *they also don't understand that a lot of the specialist's visits don't involve anything happening.*

Sometimes they expect to be treated immediately the first time they see the doctor and they don't fully understand that we have to fully assess their disease status before we could treat them and we are constrained by the government regulations. (Clinician)

The lack of understanding about hepatitis B and treatment of some patients from high prevalence countries surprised one clinician - a comment which reflects the assumptions made about hepatitis B and of the need for strengthening health service and community responses:

I somehow thought that the populations would have an understanding of it as a disease within their community ... but they don't, they have no idea ... education is a huge thing that needs to be addressed.

For several respondents, this lack of understanding and/or meaningful engagement between clinicians or health services and people from CALD backgrounds mean that some people reduce their engagement with the health care system:

There were 3 people ... who just disappeared... because they didn't understand the communication. (Program Officer)

I saw a couple of African families and ... I couldn't get messages across to them clearly, the interpreter service was letting us down, and then they just drifted off into nowhere land... they're not coming into any other part of the service, not being referred back for further follow-up. (Clinician)

Communities without the same level of access to the health care system as occurs for the majority of Australians includes Indigenous Australians, particularly those coming from more traditional communities for whom health service access can be complicated by broader cultural and historical issues:

We are talking about ... people who have English as a 2nd, 3rd or 4th language ... and they already have poor feelings about health services which have been used in a manipulative and racist way. (Community Worker)

The pattern and impact of chronic hepatitis B in Indigenous Australian communities occurs in ways which reflect the experience of developing countries. One program officer noted:

We've known for a long time that there's lots of hepatitis B among the Indigenous population and that it's principally vertical transmission, mother to child or horizontal transmission among young children ... similar to a developing country... adult transmission of hepatitis B has been relatively uncommon.

There are several programs or initiatives undertaken by the Australian governments at national and within states or territories which aim to increase access to health services by Indigenous Australians. These initiatives will have a subsequent, although not immediate, effect on reducing the impact of hepatitis B within these communities. One program officer noted that this included:

New Medicare items in Aboriginal health - better comprehensive health care [which] need not isolate STIs or hepatitis B.

The original Well Person's Health Check was developed in Far North Queensland in partnership between the Apunipima Cape York Health Council and Queensland Health. Concerns were expressed by one program officer of the expectation that hepatitis B screening through a Well Person's Health Check would equate to people being informed of a hepatitis B diagnosis - *one would hope that they would be (Program Officer)*. Another community worker was concerned of the lack of follow-up done by health services and noted *there should be more active following up of people*.

Within some Indigenous communities, given its increased prevalence, chronic hepatitis B is a greater priority for health services than hepatitis C. Services funded to reduce the transmission and impacts of blood borne viruses have needed to re-focus their work to meet the specific needs of their communities, particularly in remote areas. One community worker observed:

Hepatitis A and hepatitis B are really the issue, hepatitis C is not an issue in the Indigenous community, but hepatitis B is an issue in terms of chronic carriers. That's been a real challenge to us because we don't do it well ... although you could probably safely say that possibly 50% of Indigenous people walking through the door are chronic carriers.

Other health workers compared their experience with hepatitis C and what they felt was needed for the development of an adequate response to hepatitis B:

They [hepatitis B and hepatitis C] both need a focus – there's a huge need about hepatitis C in Indigenous communities, but at least there's activity being done.

Interventions to improve the limited health care access for people who inject drugs are recognised in several health related strategies, particularly the *National Hepatitis C Strategy 2005-08*, and this issue was raised in terms of the needs of people with chronic hepatitis B. The impact of this lack of access to health care

services was clearly stated by one community worker who noted that:

Users [people who inject drugs] do not have good access to primary health care, so it doesn't matter whether you've got vaccinations or anything else.

Health services are learning to adapt to the specific needs of marginalised populations in responding to hepatitis C. Given the pattern of hepatitis B infection and the populations affected by chronic hepatitis B, further development is needed. One health worker suggested:

The service that meets the needs of the hepatitis B patients will be quite different than the one that meets the hepatitis C patients.

Even when services were responding to addressing the poor levels of hepatitis C treatment access, there were concerns of the capacity of public hospital treatment services to address the needs of people who inject who have chronic hepatitis B.

The system doesn't really work – in terms of people accessing gastros within a tight hospital system. (Community Worker)

Much work has occurred over the past few years in increasing access to hepatitis C treatment. This context meant that some clinics were *struggling with hepatitis C treatment access (Program Officer)* – and would have problems taking on hepatitis B.

Other clinicians noted that the populations most at risk of chronic hepatitis B required re-thinking of clinic processes - *we haven't set up good systems for making treatment easily accessible for [Indigenous] people.*

There was a perception that while alcohol and drug services were starting to respond to the needs of hepatitis C, the populations affected by chronic hepatitis B were more diverse, requiring the development of more sophisticated responses:

A lot of people with hepatitis C will be engaged with drug and alcohol services, who know quite a lot about it ... whereas with hepatitis B its a much more diverse range of people with it ... [it could] be Joe Blow who comes in for his blood pressure check who might have it because he grew up in a community where it was endemic ... so he won't have access to people who are familiar with the referral pathways. (Program Officer)

While hepatitis B provides a range of challenges to health services that hepatitis C hasn't, strategies to improve hepatitis C treatment access was thought by one health worker as being useful for increasing hepatitis B treatment access:

The clinic did advertisements saying free treatment for hepatitis C – this increased numbers of people accessing treatment and of referrals from GPs and assumes that this would do the same with [hepatitis] B.

While the vaccination program in correctional settings was identified as generally successful, one community worker noted that in relation to the management of prisoners – *nothing is happening.*

One clinician noted 25% chronic hepatitis B prevalence rates within Indigenous people in prisons, and in a reflection of knowledge gaps within the prison workforce, one health worker noted an incident where:

They would screen you, and you would be hepatitis B positive, and you would be a chronic carrier with hepatitis B and they would put you in a cell with someone who was not hepatitis B positive without a vaccination ... we've addressed that.

Information provision

As noted previously, most people affected by hepatitis B come from communities who have little or no background understanding of western medicine. Much of the information available about hepatitis B is framed by clinicians using a western medical model with its interpretation and understanding of the body and disease processes. One health worker noted

We know from Chinese and Korean people from US and Canada, looking at people's concepts of disease is that their understanding of what it means to have hepatitis B is very much at variance with the bio-medical model.

Providing information to people at risk of, or who are chronically infected with hepatitis B was difficult for many communities and health workers given the complexity of the virus, with a community worker remarking – *I'm struggling to simplify our messages.*

One health worker noted their information provision to people with hepatitis B as:

The basic kind of story ... we can tell people whether they've been vaccinated, whether or not they've actually had hepatitis B or been exposed; whether they're a carrier and then there's one where they've got it and they're clearing it ... and that's the stuff that's the hardest to explain.

One community worker noted *hepatitis B is so bloody complicated*, while another felt that clinical specialists were not in the best position or have the time to effectively provide complex information to individuals – *it's not the crucial 20 minutes you get with the gastro.*

Respondents working in the hepatitis C sector particularly acknowledged the complexity of information about hepatitis B as challenging. One health worker found this complexity reminiscent of HIV:

I equate hepatitis B more to HIV than to hepatitis C – the management, testing, even the people with hepatitis B, all that is a lot more familiar in an HIV (framework).

Information and education about hepatitis B for people with chronic hepatitis B varies between and within communities. While one health worker reported that among Chinese speaking populations – *the knowledge is very poor, and information access is very poor*, another clinician reported:

All the (patients) from southeast Asia are usually well aware of their infection often they've been having regular monitoring; some of them have been placed on therapy.

Several service providers reported that the level of understanding of hepatitis B by people from Asian communities was greater than that of people from African communities. The experience within some African communities with other blood

borne viruses influenced their understanding of hepatitis B infection. One clinician noted:

The understanding of infections from some of these people from Africa is very poor ... clear about HIV ... (but) with hepatitis B it's not commonly seen as a sexually transmitted infection for a lot of these communities. It's something that they get from birth, from mother, or contracted in childhood, the concept of sexual transmission is a bit foreign to them; sexual transmission is more of an issue for developed countries.

Better access to hepatitis B related information resources was seen as important in allaying fears, particularly for families and friends of people with chronic hepatitis B – *there's not a lot of written information ... people are really fearful (Community Worker).*

Other health and community workers reported the significant impact of the lack of information for people diagnosed with hepatitis B and their families:

When you don't have good written resources to back up someone's diagnosis and allay those fears of family members, it just compounds the problem.

There really isn't much support for workers that have clients with hepatitis B ... when they go home they also need the information at that point to give to their families, which just isn't there, and all the things that we were concerned about with hepatitis C like discrimination and stigma are just being amplified because no-one is addressing these issues. (Health Worker)

We've got bugger all resources, and I'm getting more calls from people with hepatitis B ... wanting to know what they should do, and also get calls from family members with hepatitis B ... people are really fearful, so when one partner is diagnosed with hepatitis B ... the other partner is wanting to stay right away from them; won't sleep with them, won't have sex with them. (Community Worker)

One community worker working with people who inject drugs, noted confusion of this group between the different hepatitis:

Older users, or people with experience with hepatitis B assume [the hepatitis viruses are] one and the same and that they behave in similar ways. I think there's enormous confusion out there, and particularly because a lot of people will have had experience with hepatitis B and that whole cycle of getting sick, getting better and then having immunity, and thinking that hepatitis C will behave in similar ways.

In a reflection of the success of hepatitis C information provision among people who inject drugs, the same worker also noted that *it's easier to work with our NSP clients about hepatitis C.*

For people who inject coming from CALD backgrounds, one community worker noted one perspective existing of a linear progression between hepatitis and HIV, and that *you progress from hepatitis A, to hepatitis B, and hepatitis C then to HIV.*

This alternative understanding of viral hepatitis, with inherent implications for treatment access, was also noted by one man with hepatitis B who understood hepatitis as:

Coming in three levels – hepatitis A, hepatitis B and hepatitis C with hepatitis C being worse...people in Afghanistan get yellow skin when they are sick.

Different patterns of infection and sequelae also influence how communities interpret the virus and its meanings:

It's just called liver sickness ... hepatitis B is not seen as a sexually transmitted disease, because you don't get the symptoms, you don't get the genital symptoms, it doesn't have the stigma as syphilis. (Health Worker)

Hepatitis B is complex – both for professionals and for people with chronic hepatitis B. The serology; outcomes of infection; the populations in which hepatitis B is prevalent, and treatment all provide challenges for populations at greater risk of hepatitis B infection and professionals working the area. One key theme throughout the assessment was the lack of accessible and useful information available for people with chronic hepatitis B. Service providers were often unaware of the resources for people with hepatitis B, with one health worker stating – *I don't think there's any out there.*

Post-diagnosis resources have been developed targeting people with hepatitis C given the complexity of information needed to be provided, and that service providers were unable to adequately provide this information in culturally acceptable ways. There is a significant amount of complex information that is required at the point of a chronic hepatitis B diagnosis, and one issue recognised by one health worker was *a clear understanding on the natural history would be really useful to give to people.*

One person who had recently been diagnosed with chronic hepatitis B reflected the lack of information provided to her – *I don't know what to do and I don't know where to go.* This person also felt the lack of resources related to language proficiency – *if you don't speak English, nobody tells you nothing.*

Throughout the consultations for the needs assessment, confidence in the understandings of service providers and people with hepatitis B was often lacking. Viral literacy has developed in response to the transmission of HIV and hepatitis C among people most affected by the viruses and service providers; however this hasn't occurred for hepatitis B. One health worker noted that people with chronic hepatitis B – *don't know how to ask the questions in a way.*

Health workers responsible for hepatitis C workforce development and capacity building positioned hepatitis C among other hepatitis viruses by describing hepatitis, then briefly describing hepatitis B before providing information about hepatitis C. This assisted in addressing issues where *people (were) getting the hepatitis mixed up.*

The inclusion of hepatitis B information was required as one health worker noted that:

There weren't other sources of information [and] clearly they're not getting it [information] from other places.

One health worker who has successfully included hepatitis B information into resources noted that *the reason we were able to get that right, was that was what was intended at the beginning* rather than including hepatitis B as an 'add-on' to an existing resource.

One person with hepatitis B noted some of the difficulties they found in getting information about living with hepatitis B and suggested the need for a single resource specifically for people with hepatitis B:

I had to ask a couple of people because the people that I did ask didn't have all the information; they would give me bits here and there, and with the doctors they didn't have enough time to go through the specific questions.

There was general agreement throughout the assessment from the majority of respondents that *the main focus should be [on] improving accessible resources for people with chronic hepatitis B. (Clinician)*

Much of the information about hepatitis B uses a medical model for explaining the impact and scope of potential illness. This means for people with hepatitis B the future is framed in physical deprivation with one person with hepatitis B noting that:

[Hepatitis B] has always been for me ... completely medicalised. Once hepatitis B positive, always hepatitis B positive. I saw the disease progression and the liver disease and the gynecomastia and the trunk obesity and the muscle wasting and the encephalopathy and you know that's what life is going to be.

The level of information on how to reduce hepatitis B transmission, even among people who are infected was considered to be a gap. One health worker noted that for people who are chronically infected:

A lot of patients are not clear about it – how it is spread, even when they know that they have the disease ... there is a lot of misinformation out there.

There is limited information available for people diagnosed with chronic hepatitis B, while information is available from departmental sources in most jurisdictions about hepatitis B targeting the general community. One resource was developed in Western Australia in 1997 specifically targeted people with chronic hepatitis B. The amount and scope of information provided in the resource is limited, given the size of the pamphlet and the resource is not currently being distributed.

One person with hepatitis B summarised one aspect of living with hepatitis B as – *there's no guidebook.*

Treatment issues

Essential questions were raised about treating chronic hepatitis B, with one clinician wondering – *should we be treating the virus or should we be treating the liver disease?*

Clinicians spoke of their motivations in increasing access to treatment, with one clinician aiming *to stop cirrhosis*. Another clinician reported that increases in the prevalence of liver cancer had changed their hepatitis B treatment patterns:

My personal philosophy has changed quite dramatically, I'm far more aggressive in treatment now than before ... [in response] to rise in hepatocellular carcinoma.

As noted previously the communities most affected by hepatitis B are becoming more diverse, and the provision of hepatitis B treatment occurs within a changing context. One clinician noted that *the work has become increasing complex, often seeing younger patients... [and] our ethnic base is also increasing.*

Throughout this assessment, hepatitis B was described as being complex with one clinician stating:

Larger numbers of people who have had resistance to treatment, and ... the complexity of the disease amongst these patients is getting more complex.

There was also a perspective that this complexity challenges clinicians. One specialist noted:

General gastroenterologists find hepatitis B extremely complex and don't necessarily understand the disease or its treatment, which results in switching and changing medications without a rationale and can result in resistance.

One major treatment related issue over the past couple of years has been funding for DNA testing related to hepatitis B treatment. This has been resolved by an assessment of the Medical Services Advisory Committee at their meeting of the 9 March 2007 where the committee found 'sufficient evidence of the safety, effectiveness and cost effectiveness of hepatitis B assay in the pre-treatment and in the monitoring of patients with chronic hepatitis B', and that 'public funding be provided for the use of hepatitis B assay in patients with chronic hepatitis B' was recommended.

The impact of the lack of DNA testing was described by one clinician as that *we are treating a disease which is a viral disease but we can't reliably measure the virus.*

The lack of publicly funded access to DNA testing meant some patients were unable to use treatment *because they can't afford to pay for the test.*

Another major treatment related issue related to the use of monotherapy. Current government funded treatment protocols rely on monotherapy which was seen by most clinicians as a problem with its impact being described by one clinician as *resulting in a whole cohort of patients with ... anti-viral drug resistance.*

One clinician noted therapeutic lessons learned with HIV were not being used for hepatitis B treatment – *the concept of treating a viral disease with one drug when we've learnt that mistake with HIV.*

The lack of data fundamentally affects the use of monotherapy – *it is likely that combination therapy has got an important role but it's not funded because the data is not yet available. (Clinician)* In an alternative view, another clinician noted that:

Trials so far have looked at combination versus monotherapy looking at end points such as e-seroconversion and DNA reduction and long term outcomes from that ... which are still surrogate outcomes and still haven't shown any benefit ... so there is no proven benefit from [combination therapy].

One perspective from several clinicians was that pharmaceutical companies play a role in perpetuating monotherapy – *pharmaceutical companies have too much influence in lack of availability of combination therapies.*

It is as predicted that monotherapy would lead to resistance and that pharmaceutical companies wouldn't collaborate well enough to get combination therapies ... and the government is not going to look at soft trials to license combination therapy. (Clinician)

Access to government funded therapy is determined by identification of chronic hepatitis B through the use of liver biopsy. Liver biopsy was seen as a barrier to treatment access, particularly for people from CALD backgrounds, some of whom have a concept that you want to permanently damage [the liver]. (Clinician)

There were clear statements by clinicians of attitudes towards liver biopsy with one clinician suggesting to *remove the liver biopsy criteria.*

While it was noted that some patients found liver biopsy a daunting prospect, another clinician reported:

Some people don't like a liver biopsy ... most people ... probably about half of them vaguely know what it is, that it's terrifying and scary, and a painful procedure, most people I end up doing a biopsy [on] are pleasantly surprised about how minor it was.

Nursing staff were recognised as playing an important role in the provision of information and their role was acknowledged by the majority of clinicians:

Nurses are exceptional at being able to monitor and discuss a lot more openly and deeply [the] natural history of the virus.

I really need a nurse involved to track [my patients] and make sure they do come back, as we have increasing number of people on therapy ... you want to use your manpower to ensure there is compliance, follow up.

Because hepatitis B treatment and management is long term, liver clinics are required to develop processes to adequately respond to this timeframe:

I don't think we do it all that well ... hepatitis B is about life long treatment, and life long monitoring, and I don't think that we have the systems in place in this clinic to do that effectively We've got the clinical staff, but we haven't got a well-defined recall system. (Clinician)

There are basic questions about treatment which concern some clinicians. Several clinicians noted difficulty in identifying when to commit people to often ongoing therapy:

It's difficult to know when to commit someone to potentially very very prolonged therapy.

The natural history of hepatitis B is really variable and so finding the patients and agreeing who is appropriate or a treatment candidate and who can be watched ... there's some controversy over that.

The treatment algorithms are still evolving and we don't yet know when we should start treatment and what we should start with and if our current

regimes are ideal drugs to use ... it is an evolving process as more data becomes available ... it is still controversial and you can't get consensus.

Many of the people with chronic hepatitis B have experienced considerable trauma and often come from highly disrupted backgrounds. One clinician reported the impact of this on the clinic:

Huge social disruption and post traumatic stress ... psychological problems that clearly we don't address very effectively in our clinic setting.

The complexity of hepatitis B and its sequelae, and differing understandings of some aspects of hepatitis B among clinicians and other health workers further complicates communicating about hepatitis B to people from CALD backgrounds:

If you think about the number of hepatitis B specialists who argue about the natural history of hepatitis B [and] can not agree amongst themselves; and then you try to tell this person about these nuances through an interpreter. (Community Worker)

Several clinicians described patients, particularly people with Asian heritage as being 'compliant'. Other clinicians noted this compliance as a barrier to effective communication:

They are sitting there nodding saying 'yes, yes, yes, thank you very much', but they don't understand, they won't say 'what's that mean?'

Perceptions of compliance also meant that patients may not be disclosing issues of relevance to their treatment, or whether their decision to undertake or refuse treatment could be described as an informed choice – *they're easy to deal with but it doesn't mean that they're doing what they say they are doing. (Clinician)*

It's fine if they're saying 'no' [to treatment] if they know why they're saying 'no', I have no problem with that, but I'm never really convinced that in many cases that they really understand. (Clinician)

Effectively communicating with patients from CALD backgrounds is important for developing clear understandings of treatment protocols, compliance and expectations. Clinicians reported:

You're much more likely to get people who want to be treated and stick to their therapy if they understand what they're doing and they think it's good for them.

Once they've been on antiviral treatment for long time, when the resistance starts, it's hard to explain to them what is happening, and therefore hard to explain ... why you want to change medication.

How people understand disease and the body, has a profound and long-term effect on the relationship that patients have with hospitals, clinicians, treatment and treatment compliance. One clinician reported the impact of not communicating to patients in their own language:

Even if the doctor tries to tell them the problem, they cannot perceive the concept and unless you explain it to them in their own language ... they have little concept of the disease ... they have no idea what the treatment is and what the treatment does.

It was reported that inadequate communication, and limited resources required to develop effective relationships with patients had a direct impact on the choice of treatment for specific populations. Government funded treatment for chronic hepatitis B is monotherapy with one limitation being the development of antiviral resistance. These treatment choices have significant consequences on patients and their families. One clinician reported:

Everyone just put them [patients from Asia] on lamivudine because for Chinese speaking patients it was easiest; it's easy for a western speaking patient anyway, but it's even easier for a Chinese speaking patient because you don't have to explain interferon and side effects and everything else.

Few of the clinicians who participated in this assessment noted Indigenous Australians accessing the clinic in which they worked.

One clinician working in a region with a significant Indigenous population noted that Indigenous people made up *less than 1%* of their patients, while another noted *absolutely no contact with Indigenous populations*. This perception was reinforced by an Indigenous program officer who said that they'd *never heard of anyone treated for their hepatitis B*.

One of the few clinicians interviewed who was working with Indigenous people described *people dying early from end-stage liver disease and that's complicated by alcohol use ... (hepatitis B) is actually a killer and a lot of people aren't being referred in*.

Another clinician noted that when Indigenous Australians had been referred, it was late in the disease progression:

Three of them had cirrhosis but it was not diagnosed before I met them, and they'd been in hospital a couple of times, but their compensated liver disease wasn't recognised.

One community worker noted that people who inject drugs have a *poor understanding of their (hepatitis B) status and what it means*. This perspective was noted by a health worker who described hepatitis B treatment as *not on the radar, and hepatitis C is only just starting to be known about*.

General Practice

One essential group of health service providers which need to be engaged to reduce the impact of hepatitis B infection upon the community are general practitioners. One program officer noted the role of general practice being *diagnosing the unrecognised pool [of hepatitis B] ... at the general practice level*.

A one page questionnaire with 13 items was posted to 500 general practitioners (GPs) within the Northern Division of General Practice in Melbourne (the questionnaire is included as Appendix A). Ninety-five GPs responded, resulting in a 19% response rate. No follow-up was done with non-responders.

The average number of years these GPs have been practicing was 24 years, ranging from less than one year to 49 years. Most, 80%, practiced within a group, most commonly with 4 doctors.

The most important sources of information about hepatitis B for these GPs were from medical journals (25%) followed by other educational materials (leaflets, brochures etc.)(13%), lectures (10%) and books (9%). GPs were asked if they felt that they needed to strengthen their professional skills in managing patients with hepatitis B; 70% said yes.

There are indications from the data that for those GPs who have been involved in the care of people with hepatitis B for more than 5 years were less likely to say that they needed to strengthen their professional skills (63.3% compared with 87.5%).

Questions relating to testing, diagnosis and referral

Almost all GPs (95%) had ordered the test for hepatitis B within the last 12 months.

The following situations which prompted GPs to test patients for hep B were:

A history of injecting drug use	94.7
Partner has hepatitis B	94.7
Hepatitis C infection	94.7
Elevated ALT over 6 months	92.6
HIV infection	87.4
Patient is pregnant	86.3
Routine STI screen	86.3
People born in high prevalence areas	83.2
A history of incarceration	67.4
Routine screening (e.g. pre-health insurance)	61.1
Information from a Pharmaceutical Rep	4.2

Just over 80% of the GPs had diagnosed a patient with hepatitis B.

Of the 59 GPs who currently manage patients with hepatitis B the number of patients ranged from 1 to 100 with a median of 5 patients.

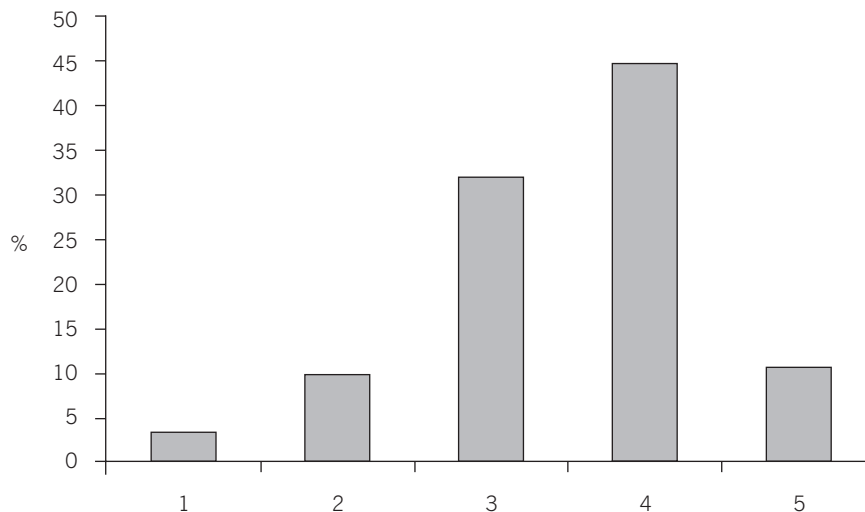
Length of time caring for patients with hepatitis B

75% of GPs had cared for patients with hepatitis B for more than five years 18% for 2–5 years. A much smaller number of GPs indicated that they had cared for patients with hepatitis B for 1–2 years (n=4). Only one GP had cared for a patient with hepatitis B for less than one year.

The percentage of patients which the GPs discussed treatment ranged from 0% to 100% with 45% of GPs stating that they had discussed treatment with all their patients.

Confidence in referring patients

Very few GPs indicated that they were not confident in referring. Only 13% (rating of 1 and 2) expressed a low level of confidence in referring a patient to a specialist, while 55% (rating of 4 and 5) were confident or very confident about when to refer a patient to a specialist (see graph 1).



Graph 1: GP level of confidence in referring a patient to a specialist

The percentage of patients with hepatitis B who have been referred to a specialist ranged from 5% to 100% with one third of GPs indicating that they had referred all of their patients.

The key indications for referring a patient were as follows:

Patient tests HBsAg+ and has abnormal ALT	89.5
Patient requires treatment for hep B	81.1
Patient requests to be referred	81.1
Patient has family history of liver cancer	53.7
Patient tests HBsAg+ and has normal ALT	32.6
Patient tests HBsAb+	29.5

There were concerns identified by program officers, health workers and clinicians that many general practitioners were not being proactive in screening or referring to treatment services:

The elephant in the room is that there are hundreds of people that health services know are chronic carriers who are not being offered anything at the moment. (Program Officer)

Screening for hepatitis B should be part of the routine health care check of populations who are at high risk ... but I suspect they are not being routinely checked for hepatitis B ... and I think that should be huge focus of GP education. (Clinician)

Access to screening for hepatitis B within CALD communities can be limited given stigma associated with hepatitis B from within those communities. One clinician noted:

We don't have our head around the cultural aspects of this ... there's hepatitis B infected individuals who don't want to come forward for testing because of the stigmatisation.

One specialist felt that the stigma associated with hepatitis B in some communities affected the capacity of general practitioners to undertake screening:

You seem to run into a cultural issue that the Asians don't like being told they've got hepatitis B – it's a shameful thing, and... even the Asian GPs don't really want to screen for it.

This perspective was not reinforced by any other respondents, and many of the people with hepatitis B noted that their diagnosing doctor was from an Asian background.

Screening for hepatitis B within some Aboriginal and Torres Strait Islander communities was recognised as challenging given the impact of a chronic hepatitis B diagnosis and the resources available to health services. One health worker reported that we *don't recommend screening because we know we can't treat it.*

This response, or lack of response, occurs in a context where hepatitis B is considered *a complicated field, because when they do the screen they're responsible for following it up.* (Health Worker)

This screening is also being undertaken by services receiving huge demands on their services without the resources available to address those demands. One program worker recognised that:

People who work in Aboriginal communities are snowed under with the day to day stuff ... people are reluctant to say that you should be screening for hepatitis B.

A program officer working in an Indigenous health organisation noted that better follow-up by general practitioners was needed as:

Some people go in and they say 'oh yeah, I was told I had antibodies', and there was no follow up ... a lot of people aren't getting the full information.

One health worker noted different patterns of engagement of general practitioners with hepatitis B than occurs with hepatitis C:

All GPs need to know about hepatitis C, because all GPs have got patients with hepatitis C.

The lack of proactive referral from GPs to specialists meant that some specialists felt that:

We are seeing a really small fraction of all the hepatitis B that is out there. So there's a lot of undiagnosed, unmonitored, un-followed, un-referred hepatitis B which means that we get late referrals and tumour referrals. (Clinician)

Reservations were expressed by one health worker of the capacity of general practice to address hepatitis C related needs, and that this was also reflected in their experience of hepatitis B:

I think there's a lot of misinformation in their ranks as well ... not only on hepatitis B but also hepatitis C.

The complexity of hepatitis B serology and the capacity of general practitioners to interpret this serology were noted as being limited, with general practitioners not being aware or responding to advances in hepatitis B treatment. One clinician thought *it's something of a mystery to them*.

I think GPs most likely manage hepatitis B quite poorly as well, a. because they don't know about the disease, and b. don't really know how to refer someone. (Clinician)

I don't believe that clinicians [general practitioners] have a good grounding in [hepatitis B] algorithms – the serology is very complex. (Program Officer)

While the serology was thought complex by most respondents regardless of their background, treatment was thought as straightforward:

A pretty complex serology, but it's a pretty simple disease to manage ... it's certainly not a difficult disease to treat. (Clinician)

One community worker noted that their advice to people with chronic hepatitis B had changed over time given the improvements in hepatitis B treatments, and because they had concerns that general practitioners were not responding effectively to the needs of people with chronic hepatitis B:

If you've been diagnosed with chronic hepatitis B, ask your GP for a referral to a specialist, because I've noticed that GPs will sit on hepatitis B in their own room for years and years and years.

There were also concerns expressed that as the majority of people with chronic hepatitis B were infected overseas and at birth, general practitioners did not necessarily have the skills to address this infection pattern:

GPs in Australia are more used to dealing with people infected as adults, while hepatitis B is more threatening if [you are] infected with hepatitis B at birth. (Program Officer)

I think as GPs, we're used to the horizontal transmission of hepatitis B, we're used to adults who get the virus and then clear the virus. It's really important in the expectations you have of the virus, how you treat the virus, how the virus is likely to behave and the outcomes. (Clinician)

The need to provide information to GPs about hepatitis B treatment and referral pathways was noted by several respondents. One program officer said:

There needs to be a lot more done with GPs – there should be awareness raising.

There's a perceptual problem ... about hepatitis B that there's no treatment that works for it, that there's no agreed upon treatment, and that's its really complicated and people don't understand it and that if you go testing people

and you find them, that it creates a whole kind of work, that you've got to try and vaccinate their household members ... so there's been reluctance to do anything about it. (Community Worker)

At the moment [there] is such an ad hoc approach to managing and referring hep B in general practice. [We] need [a] national approach and guidelines. (Health Worker)

One suggestion from a health worker was for workforce development of general practitioners to address concerns of misinterpreting serology, and that the labs should take more of a responsibility for their reporting.

Referral and shared care

Of 16 specialist clinicians who were asked when they would like patients referred, six suggested referral of people with surface antigen; four of people with surface antigen with abnormal liver function, with the remainder suggesting at the point of a positive hepatitis B result, positive hepatitis B DNA or anyone with abnormal liver function.

The survey of general practitioners undertaken for this assessment reported referral occurring when:

- Patients tests hepatitis B surface antigen positive (HBsAg+) with abnormal ALT (89.5%)
- Patient requires treatment for hepatitis B (81.1%)
- Patient requests to be referred (81.1%)
- Patient has a family history of liver cancer (53.7%)
- Patient tests hepatitis B surface antigen positive (HBsAg+) with normal ALT (32.6%)
- Patient tests hepatitis B surface antibody (HBsAb+) (29.5%)

Clinical specialists were asked for their perspective of the role of general practitioners in initiating hepatitis B treatment and shared care. While there was support for the role of general practitioners to encompass treatment – *not only can, but GPs should initiate treatment (Clinician)*, the majority of clinicians felt that much work needed to be done before general practitioner treatment initiation could occur:

Who should treat, or when someone should be treated; what's the role of the gastro; the role of the GP; the role of the nurse? There is no consensus and I think that's where things need to start.

The development of shared care protocols was also discussed with clinicians. There were variations in responses to questions about shared care, which often related to the jurisdiction the clinicians was from – with positive responses from jurisdictions which had undertaken significant activity for shared care in relation to hepatitis C. One health worker identified that *shared care is a poisonous phrase among some hepatologists*.

Again, while there was a broad range of responses to this issue, the long term nature of hepatitis B treatment was noted as reinforcing the need for general

practitioner involvement with hepatitis B:

Hepatitis B is more suited to shared care than hepatitis C ... hepatitis B treatment will last for years for most people. It's ridiculous that people who are stable need to come back to a tertiary clinic every three months for what? To say hello, get a script written and get another set of liver function tests and viral load done and sent on their way ... that's not a good use of resources. (Clinician)

A consistent issue arising throughout the needs assessment was the identification of a need for professional development to occur among public health providers, including general practitioners. One health worker reported:

I don't think that [GPs] have arrived at 'I need this information to be able to treat this patient, to refer this patient' I think this is drug companies saying treatments are around, you need to know about treatment and all that.

There was agreement however, that coordinated activity needed to occur before a comprehensive shared care protocol could be developed:

There needs to be some mechanism by which gastroenterologists [and GPs] can come to some shared understanding and agreement and that will be phenomenally difficult. (Clinician)

There were still fundamental issues related to referral pathways where it was noted by one clinician that – *some GPs don't even know that there is a liver clinic here.*

Workforce development

Hepatitis B is challenging for health and community workers who increasingly need to be more literate about hepatitis B. One program officer with professional experience as a nurse noted:

I've done hepatitis B 101 three times and every time that I think I've got it, I try to explain it to someone else and I realise that I haven't got it.

Of the 95 GPs responding to the questionnaire distributed during the development of this assessment, 70% reported that they felt the need to strengthen their professional skills in managing people with chronic hepatitis B. The practitioners also report that the most important source of information about hepatitis B were medical journals (25%), followed by other education materials, lectures and books.

Given the complexity of hepatitis B, one community worker noted the educational processes in how people, including professionals, gained and retained their knowledge of hepatitis B:

My feeling around hepatitis B education is you get a bit here, and then a bit more, and then a bit more, and then a bit more, and you just keep building on the knowledge because it's ... I wouldn't do well with 2 hours of hepatitis B right from the beginning, I would have needed lots of stuff on the way.

One community worker expressed the need of a *really good core resource ... like the hepatitis C manual [National Hepatitis C Resource Manual]*.

Several health service providers reported an increased number requests for

hepatitis B related workforce development and the subsequent need for the development of resources. This resource development was reported by one health worker as challenging given the:

Zero consensus [among experts] about epidemiology, about symptoms, about anything let alone management and what a GP needs to do to prepare someone for treatment.

The need for raising awareness and building the capacity of health services about hepatitis B among Indigenous communities was noted by one program officer:

There's hardly any information going to communities, hardly any training for workers to get up-skilled for hepatitis B, there's just not a lot out there.

The need for workforce development was also noted by Indigenous health service providers:

Because there's no national leadership on hepatitis B, and because there's no defined strategy on hepatitis B and it kind of falls in between vaccination and treatment. A lot of the AMS (Aboriginal Medical Service) doctors want more information on hepatitis B and what to do with people with hepatitis B.

Several educators noted processes undertaken in their hepatitis C training needed to include a broader discussion about hepatitis, followed by more detailed discussion about viral hepatitis. The tailoring of education for specific audiences was undertaken. One health worker reported that:

From an indigenous point of view, when I do training in Darwin, Alice Springs or Carnarvon then hepatitis B is on the agenda. When we've done training with Indigenous health care workers and community workers, then hepatitis B is an issue because we are trying to get them to understand what the conditions are that they are working within their populations. (Health Worker)

Requests were being made to services providing blood borne viral workforce development, with hepatitis B being included:

As a direct result of people saying we want hepatitis B stuff ... [in] every course we evaluate, we get asked for stuff on hepatitis B. (Health Worker)

One community worker, working with people who inject drugs noted their lack of education about hepatitis B and of the impact that this ignorance has in their work:

I haven't had any education about how hepatitis B is transmitted ... the transmission routes have never been clearly defined to me as they have for hepatitis C.

A wide range of service providers who were providing health services to affected communities were interviewed for this needs assessment.

There were instances when community and program workers disclosed their lack of knowledge about hepatitis B:

Even the natural history – I'm not clear about it ...to be honest, I don't even know if treatment is available. (Community Worker).

Examples of lack of knowledge from within health departments were also noted with one community worker being told by a departmental officer that *carriers are at no risk of liver cancer.*

One program worker with responsibility for policy development for a range of blood borne viruses discussed the different perspectives they have in responding to these infections:

Because hepatitis B has been around forever, and you think that you know about that and that you don't have to focus on it. But hepatitis C is new, and I know that I don't know anything about it, and it's happening all the time so I have to find out about that. HIV – I know that I don't know anything about it and so I have to refer everyone.

One program officer felt that professional development among general practitioners should be generated by specialists – *I think it's up to the gastros*. An example of this was given with renal clinicians undertaking the education of general practitioners after identifying that late referrals were resulting in an increased number of people requiring dialysis.

Other missed opportunities for testing and diagnosing hepatitis B infection was highlighted in the context of medical specialities involving suppression of the immune system. This includes treating patients who have cancer or lymphoma and undergoing chemotherapy who are potentially at risk of flaring if they have undiagnosed hepatitis B and are commenced on immunocompromising therapy. One clinician stated:

There are high risk areas of medical therapy that impact on hepatitis B and there's very little awareness amongst the clinicians involved in delivering those therapies. Hepatitis B is an issue, but they're not screening for it and they're not referring and they're not treating. I have been told by a medical oncologist and a haematologist ... 'we can't screen everyone for hepatitis B' ... and I just asked 'well why not?' and why aren't they?

Section 3 - Chronic hepatitis B – public policy responses

The story of the needs of people with chronic hepatitis B in relation to building healthy public policy is the absence of policy or programs specifically addressing their needs, with the exception of clinical treatment. This section looks at the priority of hepatitis B; gaps in evidence; the role of communities in responding to hepatitis B; prevention issues, and government and community based responses. A majority of stakeholders interviewed identified the need for the development of a coordinated response to hepatitis B.

The lack of strategic approach or coordination of responses to hepatitis B was identified throughout the needs assessment by community and health workers, program officers and clinicians. It was recognised that coordination for hepatitis B related to different sections within Health Departments having responsibility, but also across departments at a national level, and particularly with the Department of Immigration and Citizenship. Within Health Departments, chronic hepatitis B retains orphan status. One program officer identified that there was:

There's no champion ... everyone knows about it, but it's not considered to be an overwhelming problem in the community.

Priority of hepatitis B

The vast majority of people interviewed for this assessment identified the need for the development of specific responses to chronic hepatitis B. One program officer succinctly summarised chronic hepatitis B in Australia as follows:

There is still concern about ongoing new infections from people who are poorly informed about the disease, its risks and their potential for transmission. The big impact on health services of people who are chronically infected, either unaware or ill informed about what might be done for them is compounded by ... treatment [that] is not curative. There is going to be a significant burden from the point of view of chronic liver failure and liver cell cancer ... [and] real ongoing infection rates that will create a demand for some time to come yet. Hopefully there will be a change in our capacity to treat effectively, but that's not clearly on the agenda ... and it's compounded by the fact that the populations with hepatitis B are coming from other community groups who haven't yet got the same free access to healthcare that the average Australian born Australian has ... they're likely to be overawed by the health system and not using it like an Australian-born Australian does.

An overarching theme raised throughout this assessment was that the needs of people with chronic hepatitis B are not systemically addressed, and are not dealt with by current responses to other blood borne viral infections. Several respondents reinforced the perspective of one program officer that:

No defined strategy, no coordination of activity, no dedicated resources, very simply, that's why it never gets addressed.

Many respondents, particularly non-clinical service providers, believed that public health responses to hepatitis B were perceived as extensions with little specific focus. One health worker noted:

No-one owns hepatitis B ... HIV is owned by a range of people ... hepatitis C is owned by community organisations, gastro's etc; hepatitis B is framed under vaccination.

The positioning of hepatitis B within the public health sector was often referred to in familial terms by health and community workers:

There's the view that hepatitis C is known as the poor cousin of HIV, and hepatitis B is known as the poor cousin of hepatitis C.

We're a poor relation to hepatitis C.

I think it gets left behind ... seen as the poor cousin.

That hepatitis B is confined to specific populations was identified as being one reason for the lack of systematic responses. One health worker said:

[Hepatitis B] hasn't been given the attention in the mainstream ... it feels like the poor relation.

The focus on hepatitis B immunisation as the primary response of government meant coordinated activity to reduce the impact of chronic hepatitis B infection is not addressed. Various program officers reported:

The strategy has been basically to immunise the kids and to just accept the fact that we can't deal with the rest of it ... we're sort of aiming for eventually that most people will be immune.

The government has wanted to believe that the vaccine has solved the hepatitis B problem and not willing to talk about the vaccine more widely.

Key activity is really the immunisation program ... universal immunisation program at birth and supplemented that with adolescents and school children ... our key contribution to addressing hepatitis B.

The success of the vaccination program, and the lack of awareness or need for a coordinated response to chronic hepatitis B, was recognised by one program officer as a barrier to increasing activity for hepatitis B related actions:

Hepatitis B doesn't have a particularly strong public profile, and if it's not in the media, or the hierarchy are not being lobbied by any groups with any urgency, then that makes it very very difficult when the numbers are declining and immunisation is increasing.

There were critical views of the role of pharmaceutical companies in 'making' hepatitis B an issue, with one health worker noting *drug companies have made it [hepatitis B] an issue ... it's about them making money.*

The limited amount of available epidemiological information shows that discrete populations within the community are affected by chronic hepatitis B. Each of these populations has differing relationships with the health care system, and with hepatitis B. While it was generally agreed that there had been a lack of response to hepatitis B from government, hepatitis B also lacked priority within various communities.

The majority of people with chronic hepatitis B in Australia come from CALD backgrounds. A diagnosis of chronic hepatitis B needs to fit into a range of other

issues for people who may have newly arrived in Australia. Community workers reported:

They may not see health as their first priority ... and there is culture shock, and language barriers, and transport access.

When you're looking at the refugees, hepatitis B is not the dominant thing on their mind; creating a life here is far far far more important so when it comes to hepatitis B ... they have more important things.

Within some specific communities, particularly for people working with Indigenous communities, hepatitis B was seen as ordinary, with one health worker noting hepatitis B as an issue that is *a bit forgotten because it's been around forever*.

One health worker recognised the low priority of hepatitis B within their Indigenous health service, in spite of epidemiological evidence, because of the broader social context in which hepatitis B occurs for these communities:

It's a very low priority, because there's a lot of competing priorities ... all much more visible. I think it's [hepatitis B] a lot more important than people make out or think it is.

Prevalence of chronic hepatitis B varies between specific communities, but for many the prevalence within some Indigenous communities mean that service providers and communities develop complacency *because it is so common that people have hepatitis B. (Health Worker)*

This view was more bluntly expressed by one health worker:

[We've] gotten used to it being part of the spectrum of things that Aboriginal people have to live ... sort of a background, backdrop to other things, and so you don't have to do anything about it because it's just there.

Indigenous Australians health status is recognised by communities and government as challenging. The high prevalence of hepatitis B among some Indigenous communities meant that health and community workers accept that *hepatitis B is something that the Indigenous community has lived with all their lives*.

There are many social issues affecting Indigenous communities, and hepatitis B may not be a priority for some. One community worker noted – *how can we worry about treatment for hepatitis B when we can't even get a house*.

Several health workers and program officers saw the challenge of responding to hepatitis B within Indigenous communities as *a priority in the face of a whole range of other burden of illness*, and within a context where there is a *nihilistic approach to chronic diseases like hepatitis B here*.

As with perspectives of hepatitis B within public health, hepatitis B within an Indigenous context was seen as the *poor relation* amongst a range of other health issues affecting communities.

This perspective was also reflected in public health responses to blood borne viruses where one person working with people who inject drugs noted that hepatitis B received a low priority:

I'm well informed about HIV and hepatitis C; hepatitis B has just been a fuzzy sort of area for me, and I mean we often complain that HIV has slipped off the page, but hepatitis B has never really been on the page.

Prioritising hepatitis B within street based people who inject was noted as being difficult by one health worker:

It's their using that prioritises in terms of where they put their energy ... their feeling of sickness is more around dope-sick than other health and chronic health problems.

The effect of this for one health worker was that the *competing priorities* [for people who inject drugs] constantly push those longer term issues [such as hepatitis B] down the list.

Where a response to hepatitis does exist, it is in the context of addressing HIV or hepatitis C related activity – we *integrate it into what we are doing*. (Program Officer) This activity includes promoting the hepatitis B vaccination program in resources targeting priority groups.

While these programs provide several opportunities in which hepatitis B activity could be undertaken, hepatitis B does not receive priority or resourcing. One program officer identified the cyclical nature of the raising of visibility of hepatitis B related issues occurring over the past few years:

It's a discussion that has actually gone on for several years, and emerges and disappears essentially because the issues have been too difficult to resolve properly.

As previously mentioned, the act of researchers asking about chronic hepatitis B could have the effect of creating a problem where there may not be one. There was questioning of the priority that hepatitis B needed within departmental activity with one program officer noting:

I think the challenges that we face with hepatitis B, pale in significance in comparison with other challenges facing health departments.

This perspective was felt to be appropriate by another program officer, who felt that hepatitis B was:

[Not] on a par with hepatitis C, because the majority of adults who get infected with it will clear the infection; so you are not building a huge load of infected population like you are with hepatitis C.

The health issue priority within sections of government dealing with sexual health and blood borne viruses were clear for program workers who reported their priorities as:

Chlamydia, increasingly complex needs of people with HIV, changing workforce, increasing hepatitis C treatment [access].

Chlamydia, gonorrhoea and hepatitis C are the top priorities and hepatitis B falls somewhere lower in my order.

Program workers noted that responding to hepatitis B, particularly without additional resources, would decrease activity being done to reduce the impact of hepatitis C:

The only way we could do it at the moment ... would be to stop doing something in hepatitis C.

One program officer noted where hepatitis B was positioned in relation to other health issues:

With hepatitis B there's a lot of chronic illness, there's a cheap vaccine but there's no education, no publicity and there's no drive because other things have taken over.

Research, surveillance and epidemiology

Fundamental to any effective public health response is to identify the scope of the problem. Several program officers identified that the lack of information or research describing the impact or burden of chronic hepatitis B on the community was an important factor in the lack of an effective coordinated response to hepatitis B:

From a departmental perspective, we need to get better information around what it is, who it's impacting on.

The problem needs to be quantified.

Until there's more research done ... you need to do the research before deciding how to respond to hepatitis B.

We're not operating with the amount of information that we ought to.

This lack of information means a lack of demographic and other data to inform appropriate levels of service delivery and planning. Two program officers reported:

We haven't defined the problem enough, and who it is impacting upon. Until you do that, you don't have a sense of what are the sort of service responses that you are going to need to have in place, both the mix of services, and level of skill of the people involved, and do we already have them, but it's just that we are not utilising them for this purpose.

We need to define the burden of disease ... if we find what we suspect which it is a really common under-recognised, under-treated disease and a significant cause of morbidity ... if we find those things with hard data, then we can advocate for better funding and resource allocation.

Without a firm description of the problem, one clinician noted relying on hunches – *I think there's more newly acquired than we know.*

The majority of interviewees had experience in public health responses to HIV and hepatitis C, and several program and community workers noted differences between responses to these infections and the response to hepatitis B. One program officer identified that the impact of the unclear picture relating to hepatitis B influences funding:

I'm not sure that we have as clear a picture of hepatitis B from the surveillance point of view, as what we have with ... hepatitis C and HIV. I think it makes it more difficult because, when you try and argue a case for something to be done with hepatitis B.

Good surveillance data in developing commitment and resources from government was recognised by one program officer who noted:

We have a much better handle on the epidemiology of hepatitis C in Australia than what we do hepatitis B, which means from a departmental point of view when you base so much around epidemiology and data and statistics ... I think makes it challenging.

The health care system in Australia provides opportunities to undertake world class research on hepatitis B; however the resources and coordination available for this are limited. One health worker commented that:

If there was a sensible programmatic response to hepatitis B where I could present something sensibly and know that it wasn't going to last one year or two years, I would sit down and put energy into it.

Strengthening community responses

Communities play an important role in how hepatitis B is understood by individuals, and the level of support provided to people with hepatitis B. Several respondents noted a need for the provision of information and education to individuals and a broad range of health service providers including general practitioners. There was also a role noted for the development of community-wide support for hepatitis B related interventions.

There was recognition of stigmatising specific communities by raising the profile of hepatitis B within these communities:

You're walking a tight line a lot of the time between wanting to prioritise the target education with not wanting to stigmatise a population. (Health Worker)

The problem with aiming the education at those groups is that you run the risk of everyone else who hears about that education happening [will result in people going] urgh ... every time that [you] see someone who is Asian. (Clinician)

Raising the visibility of hepatitis B among communities, particularly people newly arrived or negotiating the pathways of immigration was identified as a risk for hepatitis B related activity. One health worker noted:

If you consider that the immigration department can exclude people on the basis of their HIV status ... one would be wanting to be rather cautious in closely identifying any one population group on the grounds that you could equally set off the alarm bells.

Strategies for addressing concerns such as this were identified by another health worker:

By saying that priority populations for any education program are those who are not active seekers of health care. So we're targeting those people from CALD communities, people from Indigenous communities, people who inject drugs ... and people who are not picked up in childhood screening.

Indigenous Australian communities are over-represented in the numbers of people chronically infected with hepatitis B with up to 3,500 Indigenous Australians with

hepatitis B and constituting 16% of the Australian population with hepatitis B. The impact of hepatitis B upon these communities is unique considering the broader social and cultural issues these communities face.

One community worker remarked on the strong historical link between hepatitis B and Indigenous communities due to hepatitis B's initial framing as the 'Australian Antigen' and its discovery among Indigenous Australians – *given the history of hepatitis B in Aboriginal communities, it was first diagnosed in an Aboriginal person.*

Chronic hepatitis B infection occurs within communities in which alcohol is recognised as an issue for the health of individuals and of the community as a whole. A clinician noted that *they [Indigenous people] die of liver disease with complications of alcohol use and hepatitis B.*

There were clear ideas for what was needed from Indigenous health services from one health worker:

People don't know that there's treatment; community knowledge ... I think they know that their babies are vaccinated for hepatitis B but don't know that vaccination is available for older people.

Chronic hepatitis B infection among people who inject drugs was described as an 'occupational hazard', which occurs within the context of sometimes chaotic lives. For the majority of people who inject drugs, who are infected at an older age, hepatitis B was not seen as an important issue given the greater likelihood of resolving infection.

For one community worker, hepatitis B did not have the importance of other blood borne viral infections:

Before HIV, hepatitis B was really the only reason not to share a syringe, but back then it wasn't really a big deal because ... how most people experienced [it] was that you might get a bit crook for a while but nobody ever died from it, and everyone got better, so it wasn't the sort of spectre in the community that HIV and hepatitis C is.

One health worker noted the focus of the provision of harm reduction education and information was on safe injecting, however this neglected hepatitis B in its capacity to be sexually transmitted. This health worker also identified that issues for people who inject from Vietnamese backgrounds *are compounded ... the issues are a bit more complex* than for Anglo people who inject given the three opportunities for exposure – perinatal, sexual and injecting.

Prevention

Chronic hepatitis B is prevented with a safe and effective vaccine, which has been available since 1982. Hepatitis B immunisation is funded through the Immunise Australia Program – a federal, state and territory initiative which seeks to increase national immunisation rates. This needs assessment focussed on the needs of people with chronic hepatitis B, however given the fundamental role of vaccination in responding to hepatitis B from a public health and departmental perspective, information was gained from many respondents about the vaccination program, and of the role of the program in government responses to hepatitis B.

There are variations between Australian jurisdictions in the availability of *funded* hepatitis B vaccination to people considered at high risk of exposure to hepatitis B infection, and for whom vaccination is *recommended*. The lack of consistency between jurisdictions also relates to the level of publicly available information about access to funded hepatitis B vaccination. In some jurisdictions, the only information available from departmental websites about the hepatitis B vaccination program is a link to the Immunise Australia Program, with detail on specific state or territory initiatives either unavailable and/or unfunded.

The hepatitis B vaccination program was seen as the basis of government and service responses to hepatitis B. The role of the program in prevention of transmission was recognised and supported throughout the assessment. One health worker commented that *we've got prevention sorted*, while a program officer noted that *[the] best prevention strategy is what we are doing*.

The importance of the hepatitis B immunisation program in terms of public health is well recognised and can't be overstated. The program and its focus on infants and young people provide a long term substantial reduction of the impact of hepatitis B on the community. One program officer noted:

From a public health perspective the most important transmission is mother to child because of the increased risk of the infection becoming chronic.

Significant gaps in the promotion of the immunisation program were noted particularly for communities for whom vaccination is recommended. One community worker reported that *I don't think vaccination is well understood, I don't think people realise that vaccination is out there*.

Several workers reported that there is a lack of clarity about which populations the program provided funded vaccination for, with one community worker noting the *lack of clarity about free access to vaccination for which target groups*.

The recent focus on the cervical cancer vaccine with health care worker training and the level of public awareness about the program highlighted for one program officer the lack of activity undertaken in relation to promoting the hepatitis B immunisation program:

We need to get it back on the agenda ... because other things have come onto the radar ... the cancer vaccine.

The vaccination program was identified as a significant success in terms of prevention and on its impact on the public health system and one program officer felt criticisms of the program were 'overstated':

We have a cohort of children coming through with more than 90% coverage, and that's not so bad.

The availability of hepatitis B vaccine was noted as an issue of concern for newly arrived migrants. One program officer suggested that *where one person is infected, all these folk need to be vaccinated*.

Within CALD communities, awareness of hepatitis B vaccination was described by one health worker as being – *very low*. Concerns were raised that the families of people with chronic hepatitis B were unaware that vaccination was available. These concerns were not reinforced during the interviews of people with hepatitis B

who often volunteered that after their diagnosis, their families and other household contacts were vaccinated.

Issues relating to the vaccination program for Indigenous Australians generally related to access to health services and of the capacity of health services to collect data on the vaccination program. One health worker from an Indigenous health service noted – *I don't think there's good data on vaccination rates.*

Data collection from services providing vaccination was identified as problematic given the nature of the three dose vaccine schedule, with one health worker noting that services were *completely hopeless on collecting data on a course of vaccination as opposed to single vaccination.*

While some service providers working with Indigenous communities questioned the level of understanding of vaccination among their community – *there's not the understanding in some communities of the effect of viruses and so on*, it was also noted that the vaccination program was well accepted within communities.

The priority of hepatitis B within Indigenous health services was reported to have changed over the past ten years, and that the existence and implementation of the immunisation program had reduced the profile and relevance of hepatitis B within these communities. One program worker reported that:

There was more discussion about it [hepatitis B] a decade ago than there is now. I think people think that when the vaccine exists you no longer have to worry about the problem, whether or not the coverage is good, or whether the treatment of those with the disease is good. It doesn't seem to be seen as a public health issue in Aboriginal health.

In more evidence of issues relating to vaccination which weren't being addressed, one health worker working with Indigenous communities noted:

A lot of vaccination failure ... I'm getting numbers of children notified with hepatitis B in-spite of them being correctly immunised.

This respondent also noted mother to child transmission of hepatitis B continuing to occur within some Indigenous communities.

This pattern of transmission reflects a failure in the implementation of hepatitis B vaccination programs, and there were concerns expressed on access to the program and of the awareness of hepatitis B among some communities. One community worker observed:

I have real issues for Aboriginal people around [that] the immunisation program is the end all or be all. Aboriginal people don't have access to the immunisation program ... I think Aboriginal communities have a great need ... for increased awareness. (Community Worker)

These concerns are not backed up by data of vaccination coverage. However, concerns have previously been expressed of the accuracy of this data.

Several health workers and clinicians noted the high levels of adult exposure to hepatitis B by people who inject, with one clinician noting they *didn't realise people would still be exposed ... where are they getting it, when are they getting it, I don't know.*

One health worker reported that of people who inject drugs using their service:

About 1/3 haven't been vaccinated; 1/3 have had hepatitis B and cleared it, and a third have been vaccinated.

One person with hepatitis B noted that their lack of education and awareness of hepatitis B played a role in them becoming infected:

I think I put myself at risk because of a myths that I heard ... I thought I had it basically.

There were specific issues related to access to the hepatitis B vaccination program for people who inject drugs. One fundamental issue was the access of people who inject drugs to primary care services with one community worker noting:

The fact that the group who has the leading exposure ... is a really hard group to access [which] makes it a challenge for public policy.

The role of alcohol and drug treatment services in addressing the needs of people who inject drugs in hepatitis C health promotion activity is one outcome being sought by the National Hepatitis C Strategy. Several respondents also saw a need for these services to be proactive in their approach to hepatitis B, including one health worker:

One of the appalling things is the lack of integration between infectious disease and pharmaco-treatment ... I mean why can't you immunise people there?

A recurring theme throughout the assessment was the lack of willingness of the health system to address the needs of people who inject drugs. This was also noted by one program officer in relation to gaps in the vaccination program:

It's not a very saleable group ... injecting drug users don't matter; you can't sell it to anyone.

This lack of willingness was also reflected in reluctance to addressing gaps in the program for people who inject drugs, and was observed by one health worker:

If you think about who misses out or who potentially misses out most on the adolescent catch-up it's the young people at risk ... IDU's ... and there's a lot of virus already circulating in that population. I think it's not good enough to do what we do at the moment which is to just to accept that 'oh there's a problem', and that you can't give away hep B vaccine to IDUs, and there's nothing we can do about it.

Several health workers and clinicians believed the difficulty met by people who inject drugs in accessing the hepatitis B vaccine would be replicated in the development of future vaccines for other health issues. This is particularly pertinent in the development of potential HIV and hepatitis C vaccines:

We want to use trials using hepatitis B as a surrogate because we do have good safety efficacy; we certainly have lots of evidence to suggest it's a problem getting people to take it, nobody has ever thought to say 'why?' Well you should ask people why they don't want it. (Health Worker)

A community worker working with people who inject reported that this group was

nonplussed about hepatitis B – *heaps of people have had hepatitis B.*

This also led to identifying a need to promote awareness of the hepatitis B vaccine to these particular communities. One community worker suggested that:

It's about getting people to take things seriously ... that's part of the issue about vaccination.

We need to do a lot more work with injecting drug users to ask them whether it's a question of knowledge or whether it's a question of availability particularly free vaccine. (Health Worker)

We should be able to give vaccine to injecting drug users tomorrow, but it's not happening. (Program Officer)

There were several pragmatic ideas for increasing access of the hepatitis B vaccination program to people who inject drugs, with one community worker suggesting:

Doing the vaccination somewhere where people are going.

Sexual health settings are pretty good at offering hepatitis B testing, and offering vaccinations, I think the drug services are probably not so good ... fairly variable. (Program Officer)

Access of prisoners to the hepatitis B vaccination program was one success of the provision of health services to this population, albeit that this reflected poorly on community-based health services:

It's one area [where] there's a positive health impact in being incarcerated ... except where remote Indigenous populations are incarcerated. (Health Worker)

You can mount an effective hepatitis B immunisation program, and effectively capture because everyone that comes into jail should have been immunised, they're predominately young. (Program Officer)

There were several other suggestions for improving hepatitis B vaccination access. Program officers noted:

We need another burst of vaccine availability for at least 5 years to pick up the stragglers.

We should be more liberal with it ... I think that if you miss out on school based, then you should be able to get it later; although this is constrained by budgets.

The prevention of hepatitis B transmission also includes the role of sexual health clinics and contact tracing of people exposed to hepatitis B. Sexual health clinics have limited resources in which this contact tracing is done, and where one health worker noted that *Chlamydia* cases are going through the roof.

There does not appear to be any systemic approach to the testing undertaken by the Department of Immigration. One health worker stated:

Interpreters are not used in a routine manner in this screening so that pre-test counselling would be minimal.

Hepatitis B testing protocols for visa applicants appears complex and performed based on the characteristics of the individual, rather than the requirements of the visa they are applying for. Community workers reported:

If they see a cut or a scar on your body then they test for hepatitis B.

If you come from Kenya in pre-departure tests, if there are marks on your body from cultural practices, then you were sent for screening tests.

One health worker was concerned about how people were informed that they were infected with hepatitis B by the Department of Immigration. The health worker described the process as:

A standard letter which they [Department of Immigration] pop in a section [saying] 'you've got hepatitis B; you're a carrier, go and see someone at your own cost ... to see that you're ok, and seek specialist treatment'. It's really confronting, they've just applied for asylum and their absolutely terrified that health will be connected to their refugee claim.

Another service provider reported that refugees found to have been exposed with hepatitis B are required to make a 'health undertaking' where people are required to contact a 'Health Undertaking Service' on arrival in Australia, and to report to state or territory health authorities for follow-up assessment. This process was derided by one clinician as:

The weirdest, most badly run system of health that I have ever come across ... it's a system which is absolutely farcical.

Departmental responses

Overall, one recurring theme throughout the assessment was the identification and limitations of a 'silo' mentality to addressing health issues by health departments. One program officer observed:

I just don't understand how the connections between things are understood at the highest level ... and not setting them up into silos.

Another program officer interpreted this as – *we treat people as diseases.*

While several program workers identified health related programs in which activity targeting people with chronic hepatitis B was permitted, there was a lack of clarity about the level to which this activity was occurring to reduce the impact of chronic hepatitis B:

There is probably very little being done specifically for people with hepatitis B although there maybe overlap with other activities within the department.

If hepatitis B is to be addressed by departments it is generally through the communicable/infectious diseases section of the department. However the capacity to undertake this work was identified by one program officer as being hamstrung by the:

Lack of strategic directional statement qualifying the issues, the priorities and no specific funding resources.

An example of one health program in which hepatitis B was noted was the *Queensland Cancer Control Strategic Directions 2005–2010* which identifies an objective of the program being to ‘prevent chronic infection with hepatitis B or C virus’. No additional funding was allocated to achieve this objective, even though the strategy notes the increase of incidence and death rates rising as a result of hepatitis B infection over the previous two decades.

Other sections of health departments were noted by respondents as having responsibility for addressing the needs of people with chronic hepatitis B. This included chronic diseases sections, although one program officer noted the focus of these sections was on:

The big ticket type diseases ... the hot ones like diabetes, obesity or heart disease [rather than] things like hepatitis B.

Another program officer noted that the chronic diseases being addressed do not include chronic communicable diseases:

I think they just don't know what to do with it ... they don't know how to do it [communicable chronic diseases] ... they don't know how to address it, and they need to ... because there's a direct relationship between them.

One program officer recognised a sense of ‘disease fatigue’ from within departmental structures, and that while much had been achieved for hepatitis C with comparatively few resources in comparison with HIV, they reported there was:

A sense that they've [Health Departments] gone a long way doing things for diseases without any real extra dollars, and they might see this as the straw that breaks the camels back. I have a growing sense that the department is trying to buy out of these diseases and to try and fit another disease into the budget will be awful.

This view of departments ‘buying out’ of developing a comprehensive response to hepatitis B was noted by another program officer:

With hepatitis B there's a lot of chronic illness, there's a cheap vaccine, but there's no education, no publicity, there's no drive because other things have taken over.

There was also activity in terms of supporting primary health care which included activity that would directly impact on hepatitis B such as opportunistic testing and treatment. There was concern expressed by one program officer that primary health care providers were not necessarily engaged with people with chronic hepatitis B, particularly in their screening role:

Need to try and do education with primary providers to support them in better identification of people who have hepatitis B early.

Funding for hospital based activity was identified as a priority for government by one program officer who noted *buckets of money are pouring out for tertiary facilities and not for anyone else.*

Hepatitis B and Hepatitis Councils

In a comparison to the public health response to hepatitis C with its the involvement of people most affected by the disease, and the development of a comprehensive response, one clinician wished *we had a hepatitis B council*.

The public health response to hepatitis B is characterised by the lack of a homogenous community affected by the virus – *there's no homogenous community with hepatitis B*, and that relationships would need to be developed with the *populations affected by people with hepatitis B*. (Community Worker)

The communities affected by hepatitis B are different for those affected by hepatitis C, and several respondents, including a community worker noted the need for developing new models of service delivery to address the needs of people with hepatitis B:

[The] hepatitis C movement started as a result of patient support groups, and I can't see that happening with hepatitis B – and it's not the model that's going to work – which is the only model that the hepatitis C community sector knows.

Several of the state/territory based hepatitis councils have provided space within their name and scope of activity to address the needs of people with hepatitis B. No funding has been provided to undertake this increased role. One worker from a council noted the impact of this and that:

We're not funded for hepatitis B or in relation to hepatitis B and we've had to develop our knowledge base for handling hepatitis B issues.

Some hepatitis councils reported receiving requests for information from people with hepatitis B but one community worker noted that hepatitis B is:

An area of total unmet need, increasing numbers of enquiries to councils which often get referred to us, a total lack of consumer information which is relevant to the populations at risk, and just this absolute impotence to get anything happening from a top down approach.

Coordination

The majority of respondents acknowledged coordinated activity was required to address the needs of people with chronic hepatitis B with one clinician suggesting *hepatitis B – we've got to get real*.

The need for a national strategy, a model used for responding to HIV and hepatitis C was questioned by several health workers and program officers – *we do manage most diseases in this country without a national strategy*, however one clinician noted a need reflected by several other respondents for *some independent focus on hepatitis B*.

Concerns about the development of another public health strategy were expressed by one program officer:

The more that you develop a strategy for every disease ... it negates the diseases you do have a strategy for.

Several respondents assumed that resources could not be justified or forthcoming for implementing a coordinated response to chronic hepatitis B and that activity would need to be undertaken within the current health structures. One clinician described an alternative response to this was that the lack of an *independent policy response to hepatitis B will compromise the response to hepatitis C*.

There were several comparisons made between the national response to hepatitis C and hepatitis B by two community workers:

Hepatitis C seems to have a greater focus ... there's strategies, they're similar in terms of prognosis.

National leadership is necessary ... and we're talking about a large number of people.

Arguments used for justifying the need for a strategy included replicating the perceived successful aspects of the national response to hepatitis C for hepatitis B:

Help the health system understand that we have to work with what we have got, and we have to be smart with making space for the implications of the morbidity burden on the program ... [including] early detection, early intervention to prevent the disease... rigorous economic analysis. (Program Officer)

Hepatitis C is really pretty well served by a national strategy ... [hepatitis B] is a problem of equity and access for people who come from migrant communities and who really don't have a good understanding of the health system, and ... recent evidence that the anti-viral treatment might modulate the disease and hopefully forestall the progression of liver cancer. (Health Worker)

It [a strategy] seems to have worked in hepatitis C and HIV ... it put it higher up on the political agenda; it created some collaboration with groups that don't naturally work together, so getting that essential involvement was the key success factor ... there's no reason to think that this wouldn't be the case for hepatitis B. (Health Worker)

The need for collaboration and of government to provide leadership in terms of hepatitis B was acknowledged by one health worker:

[A strategy] just makes people want to work together a lot more readily. Without government involvement things just don't flow the same way, the private sector works anyway they can, but it's not really to the same extent that you could get otherwise. They don't have to call it a strategy, but there has to be some level of government involvement and at the moment that is sorely missing.

Portions of the activities that would be required by a hepatitis B strategy are included within the ambit of other public health strategies. The promotion and implementation of harm minimisation interventions such as increasing safe injecting, is a key issue within the HIV, hepatitis C and illicit drugs strategies, while targeting CALD communities with education on safe sex is included in the national HIV strategy. There were clear statements of what a strategy could look like. Two program officers described a strategy as including:

Given that ethnic populations are most affected, they would be your target group; among injecting drug users it will be to stop needle sharing [which] would solve the problem, and then we increase vaccination programs to IDU.

The threads in the other strategies are similar – marginalisation – equity and access to treatment and drugs; surveillance needs are important; workforce issues – sexual health and drug and alcohol workforce.

The need for specific responses to hepatitis B was also noted by several respondents, including one clinician who recognised that *dislocating hepatitis B, hepatitis C and HIV really might be very, very important.*

There was also a plea for pragmatism from one program officer to identify:

Those things that we are going to have some capacity to take forward, rather than an overwhelming agenda.

Lessons learned from previous coordinated responses to blood borne viruses could be used to inform the development of a coordinated response to hepatitis B. One clinician recognised:

There has to be independent development of hepatitis B public policy which is not aligned with any other disease. There was the tendency with hepatitis C to line it up with HIV, and there will be the tendency with hepatitis B to line it up with hepatitis C. There are some areas where it will make sense; but if you do that the new disease is generally compromised ... there has to be some independent focus on hepatitis B.

One optimistic health worker compared the responses to HIV and hepatitis C and what could be developed for hepatitis B:

We have a chance to get it right with hepatitis B – we got it wrong with HIV, in overdrive; we got it wrong with hepatitis C, in under-drive, and there's a prospect of getting right with hepatitis B.

Priorities for a national response

One of the aims of this assessment is to describe priorities for a nationally coordinated response to hepatitis B. We have not been proscriptive in making recommendations, but have acknowledged the key stakeholders who need to be involved in achieving the outcomes supported by this report. In achieving these outcomes, lessons from the development of responses to other blood borne viruses need to be applied.

This assessment has looked at the research available describing various aspects of hepatitis B; identified some of the needs of people with hepatitis B and of people working within the health care system in relation to addressing these needs, and national and state responses to hepatitis B. The report is a first step in what needs to be a longer term and coordinated intervention.

Priority 1 – Building healthy public policy

The findings of this needs assessment illustrate that a coordinated response is critical to addressing the needs of people with hepatitis B.

Until now, public health responses to hepatitis B have focussed on securing the blood supply; providing treatment through the Pharmaceutical Benefits Scheme, and the funding and implementation of the immunisation program. Participants from all sectors identified the need for additional activity that goes beyond current public health activity and specifically addresses the needs of people with hepatitis B, some of which have been identified in this assessment.

Government were identified as pivotal in leading the development of a coordinated response and ensuring that a partnership with government, clinicians, public health professional, and communities most affected by hepatitis B be developed.

The lack of resources was identified as a major barrier in developing and implementing specific activities to reduce the impact of hepatitis B upon the community. Activity in the first instance of the development of coordinated responses must include coordination and leadership, which would have a low budgetary impact.

It is suggested that the Hepatitis Subcommittee and the Indigenous Australians Sexual Health Committee of the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis undertake an annual review of the recommendations of this needs assessment.

Outcome 1

Consistent coordinated responses to chronic hepatitis B at national, state and territory level of government.

Stakeholders

- Ministerial or departmental advisory committees on blood borne viruses/ sexually transmitted infections and/or Indigenous health
- Blood borne virus and/or Indigenous Parliamentary Liaison Committees
- Departments of Health
- Affected communities

Priority 2 – Data

Current data detailing the burden of hepatitis B are inadequate.

Measuring the hepatitis B epidemic is imperative for justifying and developing interventions to reduce its burden and participants in this assessment identified gaps in the quality and usefulness of data available through current disease surveillance structures. The difficulties in estimating the current incidence and prevalence of hepatitis B in Australia reflect the need for improved surveillance mechanisms.

This assessment provides a strong indication that there are significant questions about hepatitis B which need to be addressed. While cognisant of the lack of resources available within public health, there is strong rationale for additional research to occur to further define the scope of the impact of hepatitis B upon individuals, specific communities including Indigenous communities, the public health system and the broader community.

Outcome 2

A strong evidence base informs policy and programs outcomes.

Stakeholders

- Ministerial or department advisory committees on blood borne viruses/ sexually transmitted infections and/or Indigenous health
- Departments of Health
- Communicable Diseases Network of Australia (CDNA)
- Clinical and social research centres

Priority 3 – Prevention

Hepatitis B infection is preventable, and hepatitis B transmission has declined with the introduction of immunisation. Data from the assessment indicates that there are several populations in which coverage of the immunisation program is less than optimal. There appears to be several reasons for this including visibility of immunisation within specific communities; payment, and administration issues. Activity needs to occur to ensure that the immunisation program addresses gaps in the program, particularly among communities at risk of hepatitis B infection.

Outcome 3

All communities at risk of hepatitis B infection have ready access to immunisation programs.

Stakeholders

- Ministerial or department advisory committees on blood borne viruses/sexually transmitted infections and/or Indigenous health
- Australian Technical Advisory Group on Immunisation (ATAGI)
- Departments of Health
- Affected communities

Priority 4 – Management and Treatment

Significant barriers and challenges exist in terms of people with hepatitis B accessing treatment. These barriers range from awareness that treatment was available; the awareness of general practitioners of current treatment protocols, and when to refer through to the relationship between clinicians and patients coming from CALD backgrounds. There were few indications that treatment services were accessing Indigenous people with hepatitis B.

It has been estimated that only a small minority of people are currently receiving treatments that could reduce the risk of morbidity and mortality associated with hepatitis B infection

Effective models of care for hepatitis B need to be developed in consultation between people with hepatitis B; affected communities; community health workers; general practitioners; nurses, and specialists.

Outcome 4

People with hepatitis B have timely access to effective management and treatment.

Stakeholders

- Ministerial or department advisory committees on blood borne viruses/ sexually transmitted infections and/or Indigenous health
- Clinicians including general practitioners, nurses, and specialists through their representative bodies
- People with hepatitis B
- Departments of Health

Priority 5 – Workforce development

The capacity of the public health system and social welfare services to effectively address the clinical and social needs of people with hepatitis B, particularly given the breadth of cultures and languages of the communities in which people with hepatitis B come from is limited.

Workforce development was a need identified throughout the consultations and is vital for the implementation of an effective response to hepatitis B. The scope of this workforce development was significant with differing groups of professionals requiring professional development on a broad range of issues. The audience for this development includes specialists; general practitioners; nurses; government and other public health workers, and staff and volunteers from community based agencies working with at risk communities. The issues need to cover basic information about hepatitis B through to working with communities whose understandings of health differ from the western medical model.

Outcome 5

A skilled workforce effectively responds to the diverse needs of people with hepatitis B.

Stakeholders

- Departments of Health
- Workforce development agencies
- Community based health and welfare services
- Clinical services

Priority 6 – Information about living with hepatitis B

There are few resources available for people with chronic hepatitis B which seek to reduce the impact of hepatitis B infection. Being diagnosed with hepatitis B can be shocking, particularly when it occurs in a context of significant disturbance and without information to frame how to understand and effectively respond to the diagnosis. Resources are necessary for people to assist in explanations of the impact of infection, and treatment alternatives for people with hepatitis B. These resources need to provide information about hepatitis B in a culturally appropriate manner and accessible in a range of languages other than English.

Outcome 6

A range of resources are available to all people affected by hepatitis B and those resources are delivered in an appropriate manner.

Stakeholders

- Departments of Health
- People with hepatitis B
- Affected communities
- Hepatitis Councils

Priority 7 – Pre and post-test information

Unlike other blood borne viruses, there is no formal model of hepatitis B testing and/or diagnosis. The diagnostic event is pivotal for a person with hepatitis B for understanding and incorporating their infection into their lives. A hepatitis B diagnosis often occurs within a context of significant change or disruption, and where understandings of the body and viruses are understood in ways which are completely different from the western medical paradigm.

Outcome 7

A national hepatitis B testing model.

Stakeholders

- Ministerial or department advisory committees on blood borne viruses/sexually transmitted infections and/or Indigenous health
- Departments of Health
- Clinical services
- People with hepatitis B

Priority 8 – Engaging communities with hepatitis B

Specific communities are particularly affected by hepatitis B, and the assessment found that there were varying levels of awareness and knowledge of hepatitis B within these communities. Engaging communities most at risk of infection, or with a higher prevalence of hepatitis B will increase hepatitis B related testing; prevention strategies; treatment access, and support for people with hepatitis B.

Outcome 8

Communities most at risk effectively respond to the issues raised by hepatitis B.

Stakeholders

- Ministerial or department advisory committees on blood borne viruses/ sexually transmitted infections and/or Indigenous health
- Departments of Health
- People with hepatitis B
- Community based health and welfare agencies

Appendix A

About your practice and professional skills:

1. What year did you begin working as a General Practitioner:
2. Main type of practice (please tick ONE box only):
☐ Solo ☐ Group practice – please specify how many
3. What are your most important sources of information for hepatitis B?
4. Do you feel that you need to strengthen your professional skills in managing people with hepatitis B?
☐ Yes ☐ No

Testing, diagnosis and referral:

5. Have you ordered a diagnostic test for hepatitis B in the last 12 months? ☐ Yes ☐ No
6. Which of the following situations would prompt you to test for hepatitis B? (Please tick the boxes that apply)

	Tick		Tick
A history of injecting drug use		Patient is pregnant	
A history of incarceration		People born in high prevalence areas	
Elevated ALT over 6 months		Information from a Pharmaceutical Rep	
Hepatitis C infection		Routine STI screen	
HIV infection		Routine screening (e.g. pre-health insurance)	
Partner has hepatitis B		Other, please specify	

7. Have you ever diagnosed a patient with hepatitis B? ☐ Yes ☐ No
8. How many of your patients have hepatitis B? (if zero, please proceed to 11)
9. How long have you been involved in the care of people with hepatitis B?
☐ Less than 1 year ☐ 1 – 2 years ☐ 2 – 5 years ☐ More than 5 years
10. In what percentage of your current patients with hepatitis B have you *discussed* treatment/drug therapy? %
11. How confident are you in knowing when it is appropriate to refer a patient with hepatitis B to a specialist physician?
Not confident 1 2 3 4 5 Very confident (Please **CIRCLE**)
12. What percentage of your patients with hepatitis B have you referred to a specialist? %
13. What are your key indications for referring a patient with hepatitis B to a specialist?

	Tick		Tick
Patient has family history of liver cancer		Patient tests HBsAb+	
Patient tests HBsAg+ and has abnormal ALT		Patient requires treatment for hep B	
Patient tests HBsAg+ and has normal ALT		Patient requests to be referred	

Other, please specify

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