Environmental Scan of Hepatitis B Activities in South Australia

Statewide Hepatitis B Coordination Project
June 2013

HepatitisSA

GLOSSARY OF ACRONYMS

AHCSA	Aboriginal Health Council of South Australia
AHW	Aboriginal Health Worker
ASHM	Australasian Society of HIV Medicine
BBV	Blood Borne Virus
CALD	Culturally and Linguistically Diverse
CDCB	Communicable Disease Control Branch
CNP	Clean Needle Program
DASSA	Drug & Alcohol Services South Australia
DCS	Department for Correctional Services
GP	General Practitioner
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HSA	Hepatitis SA
MSOAP	Medical Specialist Outreach Assistance Program
PATS	Patient Assistance Transport Scheme
PWID	People who inject drugs
RAH	Royal Adelaide Hospital
RAN	Remote Area Nurse
SASBAC	South Australian Sexually Transmissible Infection and Blood Borne Virus (STI & BBV) Advisory Committee
STI&BBV	Sexually Transmissible Infections and Blood Borne Viruses
SIN	Sex Industry Network
TQEH	The Queen Elizabeth Hospital

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INTRODUCTION

In July 2012, SA Health funded Hepatitis SA for the Statewide Hepatitis B Coordination Project to operate as the overarching coordination point for activities relating to hepatitis B in South Australia. The Project is funded for 2 years to work closely with other agencies across the state, principally to:

- Prevent hepatitis B transmissions
- Enhance hepatitis B testing, diagnosis and management initiatives
- Provide workforce development that builds skills and knowledge required for hepatitis B prevention, management and support to affected communities

As a first step in the Project, Hepatitis SA decided it was necessary to map hepatitis B related activity occurring across the state. This environmental scan aimed to:

- Identify individuals and agencies who are providing hepatitis B services in South Australia
- Describe these hepatitis B services/activities
- Identify gaps in services
- Identify issues/barriers to implementation of hepatitis B services

The environmental scan will also inform the development of the first South Australian Hepatitis B Action Plan which will guide the implementation of the National Hepatitis B Strategy 2010-2013 in South Australia.

CONTEXT

It is estimated that 218,000 people in Australia are infected with chronic hepatitis B, with a significant increasing trend over the past decade. Most people living with the infection in Australia were born in the Asia-Pacific region (38%) while 10% are Indigenous Australians.[i] Based on country of birth, the prevalence of chronic hepatitis B is greater than 10% among people born in Vietnam (12.5%), China (12.3%), Taiwan (11.7%), Afghanistan (10.5%) and Cambodia (10.3%).Chronic hepatitis B is a leading cause of hepatocellular carcinoma (liver cancer); one of the few cancers over the past ten years experiencing an increasing mortality.[ii] It is estimated that by 2017, there will be a two to three fold increase in the number of hepatitis B-induced liver cancer cases and a marked increase in the number of deaths attributable to hepatitis B under current treatment patterns.[iii]

Data suggests the 'catch-up' vaccination program has impacted with rates of newly acquired infections declining significantly since 2002, particularly among the 15-19 and

20-29 age groups with the diagnosis rate for newly acquired hepatitis B decreasing from 1.4 per 100,000 (2007) to 0.8 per 100,000 in 2011. Enhanced surveillance (other than Queensland and Western Australia) suggests a 16% decrease in the proportion of cases reported as being attributed to injecting risk, although the "undetermined" source of exposure remains high at 20%.[iv]

Data from the *Surveillance of sexually transmitted infections and blood-borne viruses in South Australia 2011*, prepared by the Communicable Disease Control Branch, SA Health shows that between 2002 to 2011 there were over 2,700 South Australians diagnosed with hepatitis B with an average of 288 notifications per year from 2007 - 2011. In terms of acute infection during this period, there were 108 newly acquired infections, with a peak in 2010 of 21 newly acquired diagnoses. The distribution of unspecified hepatitis B virus infection cases among different racial groups has remained fairly constant over the past 5 years as in 2011, the distribution was 60% Asian; 14% African; 10% Caucasian; 8% Aboriginal and 8% other racial groups.

The cultural diversity of people most affected by chronic hepatitis B provides unique challenges for the health system with inadequate communication reported between people with chronic hepatitis B and health professionals, particularly clinical specialists. Limited proficiency in English has been noted as a significant barrier to effective communication with people with hepatitis B and affected the expectations and behaviours of patients in relation to clinical management.[v]

In 2010, the Australian Government developed the National Hepatitis B Strategy 2010-2013. The goal of the strategy is to reduce the transmission of, and morbidity and mortality caused by, hepatitis B and to minimise the personal and social impact of hepatitis B. The strategy acknowledges that the greatest burden of hepatitis B is experienced by people with a chronic hepatitis B infection, the majority of whom were infected at birth or as children and who may be unaware of their infection.

New infections in adults rarely lead to chronic infection and vaccination programs will largely prevent domestic acquisition in the longer term. Childhood vaccination is included within the National Immunisation Program Schedule and is funded by the Australian Government. Priority populations for vaccination to reduce new hepatitis B infections include children born to mothers with chronic hepatitis B (pregnant women) and people from communities at greater risk including men who have sex with men, people who inject drugs, sex workers, partners and other household and intimate contacts of people with a chronic infection, people in custodial settings and people with HIV and or hepatitis C.

Chronic hepatitis B disproportionately affects people from low and middle income countries. In these countries, high rates of chronic hepatitis B are related to high levels of

mother-to-child and early childhood transmission due to a lack of comprehensive immunisation programs and a secure blood supply. Priority populations with chronic hepatitis B identified within the strategy include people from culturally and linguistically diverse backgrounds (CALD) and Aboriginal and Torres Strait Islander peoples.

METHODOLOGY

A steering committee was established by Hepatitis SA for the Statewide Hepatitis B Coordination Project and consisted of representatives from key stakeholders involved in providing hepatitis B activities in SA. The Steering Committee included representatives from the Aboriginal Health Council of South Australia, viral hepatitis nurses, Hepatitis SA, Migrant Health Service, PEACE Multicultural Service at Relationships Australia, the Sexually Transmissible Infections and Blood – Borne Virus (STI & BBV) Section of SA Health, and the SA Prison Health Service.

The steering committee's role was to guide the planning and implementation of this environmental scan including identifying key stakeholders to interview; the development of interview tools; and feedback on the draft report of the environmental scan.

An interview questionnaire was developed (see appendix A), using the framework provided by the priority action areas of the National Hepatitis B Strategy 2010-2013. These priority action areas are

1. Building partnerships and strengthening community action
2. Preventing hepatitis B transmission
3. Optimising diagnosis and screening
4. Clinical management of people with chronic hepatitis B, and
5. Developing health maintenance, care and support for people with hepatitis B

A matrix (see appendix B) was also used to provide a visual reference to assist in identifying gaps in services in relation to the priority action areas and for the priority populations identified in the National Hepatitis B Strategy.

44 agencies were approached for an interview. The geographical size of South Australia and the resources available for the scan limited the level of participation by rural and remote service providers. Individual interviews were conducted, documented and a draft record returned to the interviewee for comment on accuracy of the details recorded. The interview record was then adjusted to reflect feedback, as necessary.

A successful ethics application was made to the Aboriginal Health Research Ethics Committee for approval to include interviews from Aboriginal Community Controlled Health Services (ACCHS). See appendices C & D for ethics approval and the research participation consent form.

FINDINGS

36 interviews were completed with staff at 28 agencies (see appendix E). Agency staff interviewed for this scan indicated hepatitis B services were provided to the wide range of priority populations, however many could not identify client numbers they had from the hepatitis B priority populations. Approximately 80% of services interviewed as part of this scan either did not collect hepatitis B specific data or could not easily access the data that was collected. This is a concern as appropriate and accessible data is required to inform service responses, identify trends and complexities for priority populations, and inform funding bodies in order to provide holistic responses to service provision for people diagnosed with, or at risk of hepatitis B.

Other findings from the interviews conducted are structured under the priority action areas of the National Hepatitis B Strategy 2010-2013.

1. BUILDING PARTNERSHIPS AND STRENGTHENING COMMUNITY ACTION

The National Hepatitis B Strategy 2010-2013 states that effective implementation depends on engaging the communities most affected by hepatitis B. The strategy recognises the need for collaboration between these communities and all levels of government as well as between community-based organisations and the medical, healthcare, research and scientific communities.

Partnerships and collaborations, largely based on the partnership approach established in response to HIV/AIDS and hepatitis C, are a feature of the sector responding to sexually transmissible infections and blood-borne viruses (STI & BBV) in South Australia. Generally, the STI & BBV sector builds effective relationships, and is keen to build integrated and holistic service responses for their patients/clients in relation to hepatitis B.

The priority populations affected by hepatitis B and hepatitis C overlap to varying degrees, and there are a number of services with established sector partnerships, who have increasingly been responding to both infections. This includes clinicians from the liver clinics in the tertiary setting, but also other healthcare providers from more specialist government health services such as the Migrant Health Service, Shine SA, SA Prison Health Services and Drug and Alcohol Services South Australia, as well as non-government sector services such as Hepatitis SA, PEACE and MOSAIC at Relationships Australia and the Aboriginal Health Council of South Australia.

Some of these agencies integrate partnership approaches throughout their work practices whilst for others, collaborations occur periodically and opportunistically. Understandably, those agencies with dedicated funding to respond to hepatitis B services are able to more thoroughly plan effective and collaborative approaches.

There are a number of established links between some of these key health agencies and general practitioners. The Royal Adelaide Hospital (RAH) has established shared care arrangements for the management of viral hepatitis with a range of general practitioners (GPs) across the state. Each metropolitan hospital with a specialist liver clinic has developed links with GPs in their catchment as well as with rural GPs. All hepatitis C clinical nurse consultants have been working to establish and maintain relationships with GPs while the Drug and Alcohol Services South Australia also has established relationships with GP methadone prescribers across the state.

Generalist multicultural/refugee services can play a pivotal role in promoting access to hepatitis B health services for their client groups who are often at greater risk of chronic infection. While one of the largest service providers for refugees and emerging communities did not respond to a requests for interview for this scan, other providers of such services indicated that there was little awareness amongst staff that hepatitis B was an issue for their clients. Partnerships are occurring to some extent in South Australia, however there is a need to improve linkages between all multicultural/refugee services and hepatitis B service providers.

Similarly, partnerships between Aboriginal services and hepatitis B service providers need to be further developed and awareness of hepatitis B promoted. Improving access to Aboriginal patients/clients by mainstream services requires the resources to build trusting relationships, a willingness to be flexible, and the ability to consult using culturally appropriate practices. Partnerships with Aboriginal Services are vital to promote opportunities to engage with this client group. It was suggested that a 'top down' approach was required to set up these partnership processes, as staff in these services can change frequently.

The South Australian Sexually Transmissible Infections and Blood-Borne Virus Advisory Committee (SASBAC) which guides and monitors the South Australian response, has representatives from the STI & BBV sector government and non-government healthcare providers, including an expert from multicultural / refugee health and an expert from Aboriginal health. The National Hepatitis B Strategy 2010-2013 also identifies the importance of 'a whole of government response including health, immigration, justice, housing, welfare, income support, education and community service agencies'. There are

few examples of this wider whole of government response to hepatitis B occurring in South Australia at this time.

Some local organisations, identified during this project as important future partners, may not have been identified clearly in the past or may not have had the capacity to respond to HBV due to organisational barriers, funding, or staffing levels. These include:

- Services which support refugees, new arrivals and unaccompanied minors, and migrants such as the Red Cross, Life Without Barriers, Migrant Resource Centre
- Cancer Council SA
- Primary Health Care Services, Women's Health, Community Health Services
- Medicare Locals
- Youth Services
- SA Prison Health
- Circo Detention Center's

It is important that in the future, these organisations be offered opportunities for HBV training for their staff and partnership projects with viral hepatitis sector organisations to increase HBV services for their clients.

Summary

- Established collaborations and partnerships exist between service providers in the STI and BBV sector
- Partnerships between hepatitis B service providers and agencies providing services to communities most at risk of chronic hepatitis B need to be established with new partners and strengthened with existing partners, in a coordinated manner.
- Dedicated viral hepatitis funding is required in key agencies to achieve sustainable partnerships rather than relying on passionate individuals within these agencies to enable the response to hepatitis B.
- A whole of government response to hepatitis B is yet to be developed in South Australia

2. Preventing hepatitis B transmission

Hepatitis B infection is prevented with vaccination. Funding for vaccines is provided by the Australian government, except for refugees and high risk groups, which is provided by the state, with local councils, community health centres and general practitioners delivering the actual vaccinations to the community.

The Immunisation Section of the Communicable Disease Control Branch at SA Health coordinates state-wide vaccination programs and distributes vaccines across South Australia. SA Health targets newborns and infant vaccinations, young people, refugees and other high risk groups for hepatitis B vaccination, with approximately 20,000 for newborns, 60,000 for infants, 40,000 for 10-13 year olds, and 12,000 vaccinations for high risk groups being provided per annum. South Australia is the only state with a Call Centre that provides information on all vaccines, and this Call Centre receives around 21,000 calls each year from around Australia.

Currently (2013) a free hepatitis B vaccination campaign has been funded targeting high risk groups in South Australia, including people who inject drugs, new arrival refugees, children born overseas since May 2000, sexual contacts of people with hepatitis B, men who have sex with men, household contacts of people with acute and chronic hepatitis B, inmates of long term correctional facilities, people who have had needle stick injuries, people with hepatitis C or chronic liver disease, and Aboriginal and Torres Strait Islander adults.

In addition to the routine assessment of all clients with a history of injecting drug use for hepatitis B and the provision of vaccination to eligible clients, Drug and Alcohol Services South Australia (DASSA) is a key partner in the vaccination campaign, promoting it through its Clean Needle Program sites. Promotion is also undertaken by both the peer educators from SAVIVE at the AIDS Council of South Australia and the Hepatitis SA outreach hepatitis C peer educators regarding the hepatitis B vaccination, and this campaign, to their client groups. The implementation of this campaign is affected by a lack of awareness of GPs about the campaign and the costs involved with accessing a general practitioner. It was also reported that GPs lack knowledge about the high hepatitis B risk groups and appropriate hepatitis B testing.

The Women's and Children's Hospital in Adelaide provides a clinical infectious diseases consultative health service to neonates, children, adolescents and pregnant women which has a holistic response to pregnant women and children diagnosed with hepatitis B. Each year around 3,500 to 4,500 mothers are screened for hepatitis B and a similar number of vaccinations provided. Women are generally referred on for ongoing hepatitis B management after childbirth, however ongoing treatment after childbirth may be offered to some women with complex issues, such as co-infection with HIV.

The Migrant Health Service is a state-funded specialist primary health provider conducting comprehensive health screening and early intervention to newly arrived refugees and asylum seekers. Vaccination is provided to all CALD clients who are not immune and do not have hepatitis B. Ensuring confidentiality, when following up household contacts for vaccination can be an issue, particularly when these household contacts may not be clients of the service which leads to added difficulties in contact tracing.

In the northern suburbs of Adelaide, where there are a high number of new arrivals being settled, it was reported that Playford Council offers an immunisation clinic once a month

at GP Plus Elizabeth for newly arrived refugee adults and children, with between 100 - 200 newly arrived refugees attending this clinic each month.

There was evidence that hepatitis B vaccinations are provided as required in Aboriginal Community Controlled Health Organisations (ACCHOs) in rural and regional areas, as well as in remote Aboriginal communities in South Australia. It was noted that screening practices differed across these services from not being a standard practice at one organisation to screening all adults and children at another. In one regional community it was reported that there was a gap in 'catch up' vaccinations provided in year 9 for young Aboriginal people, with anecdotal evidence of limited vaccinations due to a lack of consent forms being returned and 'no shows' on the day of vaccination. Due to confidentiality issues, these students could not be followed up in order to provide the required vaccination.

One role of the Blood Borne Virus Coordinator at the Aboriginal Health Council of South Australia (AHCSA) is to upskill member services staff to provide blood borne virus prevention programs in communities, and investigate access to the Clean Needle Program by Aboriginal and Torres Strait Islander people and make recommendations to Drug and Alcohol Services South Australia to increase access.

SHine SA is the lead sexual health agency in South Australia and provides hepatitis B vaccination to their priority population groups, which are mainly people under 35 years of age, including Aboriginal and Torres Strait Islanders, humanitarian entrants, people with disabilities, people who are same sex attracted, and sex workers. Clients, who are unaware of their immunization status, and with permission, are screened and vaccinated as appropriate. Clients diagnosed with hepatitis B are referred to specialist services as SHine SA does not offer ongoing monitoring or treatment.

SAPHS offers all new prison entrants vaccination on request. Hepatitis B vaccinations are recorded per individual record (due to lack of access to any electronic health record reporting), but not as an overall figure, so total annual vaccinations cannot be provided. A full course of hepatitis B vaccination cannot be guaranteed due to regular prisoner movements, and prisoners are not checked for seroconversion after vaccination. Prisoners also decline vaccinations or appointments due to competing interests. Condoms are available in South Australian prisons, but it is reported that dispensing machines are not restocked regularly at all sites.

The Juvenile Justice system was not included in this scan, thus information about vaccination for young people within juvenile detention is not available.

The National Hepatitis B Strategy 2010-2013 supports accelerated vaccination, and the Immunisation Section at SA Health has responded to requests from the SA Prison Health Service and an Aboriginal medical service to provide these accelerated doses.

Summary

- The hepatitis B vaccination program is largely being successfully implemented within South Australia
- The success of the current hepatitis B vaccination program for people from high risk populations is affected by a lack of GP awareness
- There is inconsistent implementation of screening and catch-up vaccinations among some high risk populations

3. Optimising diagnosis and screening

Appropriate screening and a coordinated and consistent hepatitis B diagnostic testing process will reduce the personal, clinical and social impact of hepatitis B infection. It is estimated that one third to a half of all people with chronic hepatitis B have not been diagnosed, are unaware of their infection and unable to take action to reduce the impact of infection on themselves or their families. The National Hepatitis B Testing Policy was developed in 2012 to support effective testing and screening.

There is evidence of appropriate screening and consistent hepatitis B testing occurring in pockets across South Australia. This is primarily among general practitioners with an interest in blood-borne viruses and high caseloads of patients with hepatitis B, as well as specialist healthcare service providers in both primary and tertiary healthcare settings.

Specialist primary healthcare providers including the Migrant Health Service in metropolitan Adelaide and the Kakarrara-Wilurrara Health Alliance, a multidisciplinary team of health professionals providing chronic disease management to one remote Aboriginal community report appropriate screening and diagnosis for their clients. SHine SA incorporates hepatitis B as part of a sexual health assessment of their clients, and testing depends on the level of risk assessed. Similarly at the Women's and Children's Hospital, pregnant women are routinely screened and Drug and Alcohol Services South Australia has a specialist viral hepatitis visiting service that provides screening of high risk clients. Viral Hepatitis Clinics, based in hospitals report providing hepatitis B screening to patients with other liver disease, but notes that usually screening has occurred in the primary health setting.

The SA Prison Health Service reported that hepatitis B screening is offered to all new admissions to prisons where SAPHS provides healthcare, although there is no formal system or specific procedure involved. If a diagnosis occurs, the individual medical officer concerned makes the notification to SA Health, and it is not tracked centrally.

Nursing staff from rural/regional area community health services, including ACCHOs, as well as hospitals suggest that routine hepatitis B screening does not occur consistently across the state. It is not known if screening for HBV is routinely occurring for all pregnant women in South Australia.

Many interviewees identified barriers to providing appropriate hepatitis B testing and diagnosis involved general practitioners being unable to identify the hepatitis B priority populations; their lack of awareness/knowledge about the need to screen the populations most at risk, about the hepatitis B testing requirements and interpretation of test results, as well as the persistence of the 'healthy carrier' myth.

Summary

- The National Hepatitis B Strategy 2010 - 2013 states 'approximately one third of people with chronic hepatitis B are undiagnosed'. Knowledge of priority populations, screening, diagnosis, treatment and appropriate referral processes are required in order to meet the future needs of people with HBV and to prevent liver cancer and/or liver failure.
- Screening is being effectively conducted only in some services
- The National Hepatitis B Testing Policy has not been implemented in services, and GPs and allied healthcare workers are largely unaware of the populations needing to be screened or appropriate testing protocols
- There is a gap between immunisation recommendations as identified in the Immunisation Handbook and what SA Health fund (ie prisoners)

4. Clinical management of people with chronic hepatitis B

Increasing the number of people accessing clinical services for the management of chronic hepatitis B is imperative to reducing the burden of infection. The National Hepatitis B Strategy 2010-2013 notes that only 2% of people with chronic hepatitis B receive any clinical management for their infection.

In South Australia, liver clinics at tertiary hospitals provide comprehensive management of hepatitis B patients, including triaging, monitoring and treatment as required, and screening and surveillance for hepatocellular carcinoma. Referrals are provided to other hospital services such as to psychiatrists, dieticians and social workers as needed and referrals to non-hospital services. Interpreters are regularly used where there are language issues and when available, information resources in relevant languages are distributed.

Flinders Medical Centre reported they managed 36 patients with hepatitis B in 2012 while at the Royal Adelaide Hospital (RAH), around 50 patients have accessed interferon treatment for hepatitis B, with 10 patients participating in hepatitis B clinical trials since 2006. It was noted that patients with hepatitis B are lifelong patients, and the number of patients is expected to grow steadily as families from high risk countries settle in South Australia.

Hepatitis B treatment and transplant case management is provided at the Liver Transplant Unit at Flinders Medical Centre. Over a 20 year period, there have been approximately 700 referrals for liver transplant consideration and of these, 10% have hepatitis B (70). General transplant education is provided that highlights hepatitis B as a causal factor in liver cancer and a significant number of patients with hepatitis B related cirrhosis, also have liver cancer.

Appropriate and timely referral to the Liver Transplant Unit enables appropriate care management. The Unit has put together some information packs, targeting culturally and linguistically diverse patients and the importance of medication compliance, as well as general liver disease packages. Internally within the Flinders Medical Centre, the Viral Hepatitis nurses, Chronic Liver Disease Nurses and Liver Transplant team work in partnership to provide a holistic and multi disciplinary approach to patients.

The Migrant Health Service doctors manage 80-100 clients with hepatitis B each year, which is around 10-20% of their clients. A Nurse from the MHS attends viral hepatitis clinics at the RAH to update HBV clinical skills and also attended the hepatitis B update provided by ASHM. This Nurse now interacts with all HBV clients, discussing the ramifications of chronic HBV, monitoring requirements, vaccination of household contacts, and answers any questions. Support for this role is provided by the Senior Medical Officer.

Drug and Alcohol Services South Australia manages treatment of clients with hepatitis B through its specialist viral hepatitis visiting services.

GPs with a special interest in HIV and blood-borne viruses, and who are s100 prescribers for HIV treatments can provide hepatitis B treatment where a patient is co-infected with HIV and HBV, although under current regulations they are unable to prescribe for hepatitis B mono-infection.

Since April 2013 and ongoing, an Infectious Diseases Physician and Ultrasonographer, together with ultrasound machines, have a contract through the Medical Specialist Outreach Assistance Program (MSOAP) to visit Yalata and Oak Valley 3-4 times per year in order to monitor the liver health of Aboriginal people with HBV in these communities. As well as monitoring their chronic hepatitis B according to evidence based guidelines, treatment can be initiated with maintenance prescribing being provided by the Medical Director of the Kakarrara Wilurrara Health Alliance, who is an s100 prescriber.

In remote Aboriginal communities barriers to clinical care include people with hepatitis B being required to travel to Adelaide for treatment and it was reported that at Yalata and Oak Valley, prior to the arrangements put in place since April 2013, nurses had driven 5 hours each way to Ceduna to assist clients to catch a bus to Adelaide, which equates to 4 days of nursing time. The Patient Assistance Transport Scheme (PATS) does not fund family members to travel to support a patient, which is then an additional cost for the Health Service. The red tape involved with applying for PATS assistance requires a level of compliance that can be difficult to maintain particularly when added to language, culture, and other disadvantages. If compliance to the process is not adhered to, it may mean a refusal for further assistance in the future. Upfront costs can also be prohibitive for individuals experiencing financial hardship.

There are only two fibroscans in South Australia, both non-mobile units, located at the Royal Adelaide Hospital and at the Flinders Medical Centre. Mobile fibroscans are available in other states to meet the needs of rural and remote communities, and the lack of a mobile fibroscan in South Australia was noted as a barrier in remote Aboriginal communities, where if one were available it would mean there was less need for patients to travel to Adelaide.

The RAH provides specialist services to South Australian prisons, with a clinic being provided at Yatala Labour prison and basic video conferencing with webcam and laptop to connect to rural prisons. Once treatment for hepatitis B commences in prisons, it was reported that it works well. However there can be limitations on the duration of treatment if a person is released after a short time, or is unwilling to commit to long term treatment, which may increase the risk of drug resistance.

Multiple systemic barriers were reported in the clinical management of prisoners with the lack of electronic patient files meaning there is no recall systems or formal procedure or systems to track the progress of patients with a specified clinical condition, such as hepatitis B infection. Movement of prisoners both within and across prisons challenges the follow up and monitoring of all chronic conditions. Nursing expertise and consistency of management of hepatitis B across prison sites was reported to be highly variable. Clinic space is inadequate and overcrowded with clinics generally being very old: this is slowly being remedied, and nurses at many sites are being innovative by providing ‘satellite clinics’ in various prison wings. Security classification and/or the gender of prisoners allowed to attend the Prison Health Centre at any one time, limits prisoner access to healthcare generally with institutional security and unanticipated ‘lockdowns’ limiting access. Access issues can also affect visiting staff (with delays due to escort requirements, prisoner movement or security requirements) and patients (with delays or inability to attend due to movement or competing demands).

Access to external appointments such as outpatients in a hospital clinic can be impacted on by prisoner movement restrictions and there can be a problem with the need for upcoming appointments not being communicated to all relevant personnel within the prison. Prisoners in rural sites often decline transfer to a metropolitan prison for medical / health reasons out of fear they will lose highly valued and hard won privileges – both whilst within the higher security prison at Yatala as well as on returning to their original

site. Options for treatment may be limited by associated costs and dependant on budget constraints. Currently, systematic hepatitis B testing and treatment is not within the current budget of the SA Prison Health Service.

There were many barriers to the clinical management of people with chronic hepatitis B identified. These were mainly in relation to specific populations affected. For culturally and linguistically diverse populations, the barriers to clinical management identified included:

- language and literacy including a lack of resources for new and emerging communities, noting that many of these people are illiterate in their mother tongue
- newly arrived having other priorities such as grief, loss, trauma, settling into a new country
- people who may not have had access to health services in the past and have limited understanding of the importance of medication compliance
- asymptomatic disease affecting monitoring compliance
- stigma
- language, culture, gender not always being considered or well understood by service providers

Additional barriers were reported for Aboriginal and Torres Strait Islanders including:

- avoidance of hospitals unless there is a crisis
- transient mobility of the Aboriginal population affecting access and long term compliance to medication leading to the possible development of resistance to medications
- tertiary services not catering effectively to Aboriginal health care

For people who inject drugs, the main barrier reported was in relation to a lack of priority given to hepatitis B in their lives, due to a lack of knowledge about the infection and other issues being more pressing.

SA Health policy does not allow for SMS text message reminders to patients regarding specialist appointments. This process is used extensively in private practice to remind patients and can limit the amount of 'no shows' at specialist clinics. If the rescheduling of an appointment is missed, it may result in a return to the waiting list for the patient/client leading to delayed monitoring or treatment.

High caseload GPs reported barriers to clinical management for their patients with one noting Medicare audits as being a disincentive to provide holistic care for patients. While patients may qualify for a GP management plan and often may request one, as is their right, the GP may not be able to provide them to all, as it can take them over the 95 percentile required by Medicare to prevent an audit. Medicare audits can be difficult and stressful and can lead to GPs acting in ways to prevent the possibility of such an event. High caseload GPs also expressed frustration that it was unnecessarily difficult to become

an S100 provider in relation to hepatitis B, especially when they were already S100 prescribers for HIV and hepatitis C medications, as this would enable them to offer localised and accessible monitoring and treatment for people diagnosed with hepatitis B.

Liver Clinic staff reported that GPs were not referring on to specialists and viral hepatitis clinics due to a lack of knowledge about hepatitis B and referral requirements. Other barriers they reported included waiting times for specialist appointments, and low levels of patient knowledge about hepatitis B, particularly the importance of monitoring and adherence to medication regimes. It was suggested that GP Practice Nurses and SAPHS Nurses can be invited to visit the Viral Hepatitis Clinics in tertiary centres in order to increase their skills and build awareness of referral pathways.

Summary

- There is appropriate clinical management of people with hepatitis B available in some specialist primary healthcare settings and at liver clinics in the tertiary sector. The option for nurses to upskill via Viral Hepatitis Clinic visits is possible.
- There are multiple barriers to accessing and understanding clinical management for many of the priority populations
- GP and allied healthcare providers lack of knowledge was the factor most often identified as a barrier to responding to patients and for patients to access services across the sector
- Timely referrals to appropriate care for patients at different stages of hepatitis B was a concern
- SA Health SMS text messaging policy for specialist appointments may be affecting the number of patient 'no shows' and the opportunity for rescheduling appointments
- Significant barriers exist in approving hepatitis B S100 prescribers in SA
- Access to clinical management for rural and remote patients had numerous barriers including lack of appropriate transport options, and lack of a mobile fibroscan

5. Developing health maintenance, care and support for people with hepatitis B

The National Hepatitis B Strategy 2010-2013 identifies that '*an increased understanding of hepatitis B infection and support for those who are infected, at a personal and community level, will help reduce the burden associated with acute and chronic hepatitis B infection and improve health outcomes.'*

Information and support services play a large role in building awareness of hepatitis B complexities at a personal and community level, and these services are increasingly being undertaken by the non-government sector in South Australia. Several non-government organisations, initially funded to provide hepatitis C services, have more recently received funding from SA Health to provide hepatitis B services, or have had their funding specifications amended to 'viral hepatitis', with no additional funding provided.

MOSAIC at Relationships Australia, provides counselling and case management services for people affected by HIV and viral hepatitis. MOSAIC counsellors have developed an outreach approach and attend liver clinics at various hospital and community sites and the Adelaide Women's prison. Of the 90 MOSAIC clients, over the past 6 months MOSAIC has worked with approximately 6 clients with hepatitis B or household contacts of those people diagnosed with hepatitis B.

PEACE, also at Relationships Australia, is a statewide service providing information, support, referral and advocacy services for culturally and linguistically diverse people at risk of or living with viral hepatitis, HIV and/or problem gambling. Referrals to PEACE from health providers usually occur when their patients have complex cultural needs and in the past year, approximately 10 clients living with hepatitis B and 30 people affected by a hepatitis B diagnosis have accessed PEACE and received intensive support. PEACE also works to improve the capabilities and confidence levels of service providers managing the health needs of CALD people by providing cultural competency training and consultation services.

Hepatitis SA provides information, education and support services for people with viral hepatitis. The Hepatitis SA Helpline is a statewide telephone service and, with associated support services, aims to provide South Australians affected by viral hepatitis with accurate information to improve health literacy and enable informed decision making in relation to viral hepatitis. Enquiries to the Helpline are overwhelmingly related to hepatitis C, but over the past 3 years, hepatitis B enquiries have increased from 58 in 2010 to 81 in 2012, with most of these being from people directly affected by hepatitis B.

The Information and Resources program at Hepatitis SA has distributed over 13,500 hepatitis B specific resources over the past 2½ years. The program also develops resources which have included a targeted awareness campaign for the ethnic Chinese community in South Australia, with small grant funding from Hepatitis Australia, and a basic hepatitis B information resource, with an unrestricted grant from a pharmaceutical company.

Agencies responsible for responding to culturally diverse clients reported the importance of having resources written in their client's own language and that where resources are interpreted from English they often do not always have the same meaning or context. There remains a lack of comprehensive information resources in relation to hepatitis B, and this is particularly the case for resources developed in other languages and culturally appropriate resources for Aboriginal and Torres Strait Islander people. For some individuals and communities, written resources will not be the most appropriate way to provide information due to a lack of literacy in their first language.

Hepatitis SA also provides education services in relation to viral hepatitis, and while education services are principally funded for hepatitis C, workforce development over the past year has also been funded for hepatitis B. During this period, more connections have been made to organisations working with high risk communities to provide their staff with

hepatitis B education to increase their knowledge to assist them to better support their clients and link them to appropriate services.

Hepatitis SA has established other partnerships over many years, such as that with Community Access and Services (the Vietnamese Community in South Australia) which has enabled the delivery of hepatitis B education to this community. The recent funding of the Statewide Hepatitis B Coordination Project at Hepatitis SA, has also contributed to more collaborations with PEACE and other multicultural organisations in delivering hepatitis B community education to some of the high risk culturally and linguistically diverse communities. Collaboration is easier where specific hepatitis B funding exists in agencies, such as at PEACE and at the Aboriginal Health Council of South Australia (AHCSA). The Aboriginal Blood-Borne Virus Coordinator at AHCSA is funded to coordinate HIV and viral hepatitis services to Aboriginal and Torres Strait Islanders through Aboriginal Community Controlled Health Organisations in South Australia.

PEACE and the Hepatitis SA Helpline both report a lack of awareness about their services amongst healthcare providers, and a lack of understanding about how their services worked, which they believed resulted in a lack of referrals.

Within correctional settings, support is provided by nursing staff for pre and post hepatitis B diagnosis only. There is limited hepatitis B education for prisoners by the SA Prison Health Service and is usually offered to individuals opportunistically due to constraints in access for prisoners for group health education. Minimal hepatitis B written resources are available and provided to prisoners who access the prison health service. Hepatitis SA educators promote hepatitis B vaccination and describe some of the main differences between all the hepatitis viruses in their hepatitis C education services for prisoners, but apart from this, there are no specific hepatitis B education services provided to prisoners by non-government organisations.

Summary

- Non-government information and support services are available for people with hepatitis B, but there is a lack of awareness about these services which limits referrals
- Opportunistic development and dissemination of resources is conducted, although this has not been systematically done
- The lack of hepatitis B resources in general, and in priority population languages, limits awareness of hepatitis B and access to services
- There are significant barriers for prisoners to access hepatitis B information and support services.

RECOMMENDATIONS

PRIMARY RECOMMENDATIONS
1. Partnerships / linkages between hepatitis B service providers and multicultural/refugee services and Aboriginal services be established and/or strengthened, in a coordinated manner
2. Hepatitis B awareness and education services are targeted to the priority populations in a culturally appropriate manner and in partnership with communities most affected
3. Appropriate hepatitis B information resources, focusing on priority population languages, are developed in consultation with the relevant communities
4. Dedicated viral hepatitis funding is provided / maintained to key agencies to develop sustainable partnership responses to hepatitis B
5. Hepatitis B education is targeted to GPs and allied healthcare providers including the full range of clinical information, as well as information on identifying priority populations, support services available in the community, and appropriate referral practices
6. Implementation of the National Hepatitis B Testing policy is promoted to GPs and allied healthcare providers
7. A standard hepatitis B data set is implemented by all service providers to inform the response to hepatitis B in South Australia
8. The uptake of hepatitis B vaccination for young aboriginal people in rural and remote communities is further investigated for efficacy
9. The Patient Assistance Travel Scheme for remote Aboriginal people

requiring medical treatment in Adelaide is reviewed in relation to meeting the needs of these communities
10. Systemic barriers to access appropriate healthcare for prisoners with hepatitis B and other chronic conditions be raised with DCS by SA Health. SA Health to consider reviewing the provision of funding for HBV health care for prisoners.
11. HBV training visits to tertiary centres providing viral hepatitis clinics be made available and promoted to GP Practice Nurses, SAPHS nurses and other appropriate nursing staff.
SECONDARY RECOMMENDATIONS
1. Mobile fibroscan/s be purchased to enable clinical management options for priority populations/communities living in rural and remote areas
2. GP S100 prescriber for hepatitis B medications in South Australia be facilitated by SA Health in order to enable localised and accessible care
3. Discussions with Medicare be held by SA Health re auditing implications when GPs specialize in the treatment of BBV&STIs
4. SA Health's text messaging policy be reviewed to allow a trial of appointment reminders at specialist clinics to measure the impact on level of 'no shows'.
5. A standard procedure be developed for patients presenting at hospitals with liver failure to ensure timely referral to the Liver Transplant Unit

FOOTNOTES

[i] MacLachlan JH, Allard N, Towell V, Cowie BC. The burden of chronic hepatitis B virus infection in Australia, 2011. Australian and New Zealand Journal of Public Health. 2013.

[ii] Amin J, Dore GJ, O'Connell DL, Bartlett M, Tracey E, Kaldor JM, et al. Cancer incidence in people with hepatitis B or C infection: A large community-based linkage study. Journal of Hepatology. 2006;45(2):197-203.

[iii] Butler JR, Korda RJ, Watson KJ, Watson AR. The impact of chronic hepatitis B in Australia: Projecting mortality, morbidity and economic impact. Canberra, ACT: Australian Centre for Economic Research on Health, 2009.

[iv] The Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2012. The Kirby Institute, the University of New South Wales, Sydney

[v] Wallace J, McNally S, Richmond J, Hajarizadeh B, Pitts M. Managing chronic hepatitis B: A qualitative study exploring the perspectives of people living with chronic hepatitis B in Australia. BMC Research Notes. 2011.

APPENDIX A

Statewide Hepatitis B Coordination Project – Questions for Environmental Scan

Name of Organisation:

Person being interviewed: Role :

Overview of Service:

1. Location/boundaries:
2. Who are your Target Population groups? Who else utilizes the service?
3. What services are provided specifically relating to hepatitis B ?
4. Approximately how many clients would you provide a Hepatitis B service for?
5. Do you have any particular approaches when providing hepatitis B services to your target group?
6. In what ways does your service build partnerships and strengthen community action regarding hepatitis B?
7. Can you identify any factors that enable you to provide these services?
8. What funding, that focuses on blood borne viruses and/or sexually transmitted disease, exists for your service? How is it utilized? Where does it come from?
9. Can you identify any gaps or barriers that:
   9a. may impact on your agency responding to clients with hepatitis B concerns?
   9b. may impact on clients with hepatitis B accessing your service?
10. How might these gaps or barriers be addressed?
11. What would enable your agency to assist with this work in the future?
12. Where does staff from your service access information/resources/professional development re hepatitis B?
13. Is there anything else you would like to add?
14. What other services/organisations would you suggest I interview to inform this scan?

APPENDIX B

Organisation/Agency:

	1. Building partnership & strengthening community action	*2. Preventing hepatitis B transmission*	*3. Optimising diagnosis and screening*	*4. Clinical management of people with chronic hepatitis B*	*5. Developing health maintenance, care and support for people with hepatitis B*
ATSI					
CALD					
Children born to Mothers with hep B					
Partners and household/ intimate contacts of people who have acute or chronic HBV					
Men who have sex with men					
Sex workers					
People who inject drugs					
People in custodial settings					
People with HIV or hep C					
Healthcare or emergency service workers					
Vulnerable populations incl: homeless & people with mental health issues					

APPENDIX C

CONSENT FORM

Project Title: Hepatitis B Environmental Scan

Researcher's name: Elaine Lloyd (Laney)

- I have received information about this research project.
- The research project has been explained to me and I fully understand the purpose and my involvement in it.
- I understand that I may withdraw from the research project at any stage.
- I understand that I may not directly benefit from taking part in the project.
- I understand that while information gained during the study may be published, I will not be identified and my personal results will remain confidential. If other arrangements have been agreed in relation to identification of research participants this point will require amendment to accurately reflect those arrangements.

Name of participant: ----------

Signed: ---------- **Date:** ----------

I have explained the research project to the participant and believe that he/she understands what is involved.

Researcher's signature and date: ----------

APPENDIX D

ABORIGINAL HEALTH
RESEARCH ETHICS COMMITTEE

18 March 2013

Elaine Lloyd
Hepatitis SA
PO Box 782
Kent Town SA 5071

RE: Hepatitis B Environmental Scan
REFERENCE NO: 04-13-499

Dear Elaine

Thank you for submitting your research project *Hepatitis B Environmental Scan* on the 7 March 2013 for ethical consideration.

I am pleased to inform you that this proposal has met with support and that the committee has decided that your application be recommended for approval. While this proposal has been approved, the committee wished to advise that a formal process for providing informed consent is needed for every participant and this requirement needs to be added into page 5 of your proposal (at F9). In addition, the committee wanted your assurance that any identifying information of participants was separated from the data provided by them. The duration of approval is from 7 March 2013 until the expected completion date of your project indicated as 30 June 2013.

In accordance with the NHMRC guidelines, *National Statement on Ethical Conduct in Human Research* (2007), we require at regular periods, at least annually, reports from principal researcher(s). An 'Annual Progress or Final Report' template is available at: http://www.ahcsa.org.au/research-ethics/

If you require any further information please do not hesitate to contact the Executive Officer or myself. We wish you well with the project and look forward to receiving a copy of your report.

Sincerely yours

L J Evans

MS LUCY EVANS
CHAIRPERSON
Ref: Proposal/Approval/7March2013

Aboriginal Health Council
of South Australia Inc.

AHREC is a sub-committee of AHCSA

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APPENDIX E

Agencies whose staff participated in interviews

- Aboriginal Health Council of South Australia
- Australasian Society for HIV Medicine
- Berri Hospital
- Coober Pedy Community Health Service
- Drug and Alcohol Services South Australia
- Flinders Medical Centre – Chronic Liver Disease Unit
- Flinders Medical Centre – Liver Transplant Unit
- GP Plus, Elizabeth
- Hepatitis Australia
- Hepatitis SA
- Kakarraka Wilurrara Health Alliance, Oak Valley
- Migrant Health Service
- MOSAIC Counselling Service, Relationships Australia (SA)
- Murray Bridge Community Health Service
- O'Brien St Clinic
- PEACE Multicultural Services, Relationships Australia (SA)
- Queen Elizabeth Hospital – Liver Clinic
- Riverside Family Medical Practice
- Royal Adelaide Hospital – Clinical Trails
- Royal Adelaide Hospital – Viral Hepatitis Centre
- SA Health – Immunisation Section
- SA Health – STI&BBV Section
- SA Health – Surveillance Section
- SA Prison Health Service
- SAVIVE
- SHine SA
- Umoona Tjutagku Health Service, Coober Pedy
- Women & Children's Hospital - Microbiology & Infectious Diseases


HepatitisSA