Hepatitis B testing and diagnosis experiences of patients and primary care professionals in Australia

Jacqueline Richmond, Elizabeth Smith, Jack Wallace, Duane Duncan, Jayne Lucke

Background and objective
A significant proportion of Australians with chronic hepatitis B (CHB) remains undiagnosed and unaware of their risk of liver disease and cancer. This study explored the hepatitis B testing and diagnostic experiences of people with CHB, general practitioners (GPs) and primary care nurses.

Method
Semi-structured interviews were conducted with people who have CHB (n = 19), GPs (n = 14) and nurses (n = 5).

Results
The majority of patient participants with CHB were not provided with information prior to being tested, and were shocked to receive a diagnosis. Neither GPs nor nurses noted Australia’s National hepatitis B testing policy as guiding their practice, and hepatitis B contact tracing was poorly executed.

Discussion
Patient participants’ diagnostic experiences did not correspond with national policy recommendations. GPs and nurses need resources to provide accurate information when testing and diagnosing hepatitis B, and clear guidance about their role in contact tracing.

Chronic hepatitis B (CHB) is the leading cause of primary liver cancer in Australia, which is one of the few cancers associated with increased mortality over the past 10 years. Of the 239,167 Australians with CHB, only 62% have been diagnosed (n = 148,284), meaning that 38% are unaware of the opportunities to reduce their chances of developing serious liver disease, including liver cancer.

Historically, Australia’s public health response to CHB has focused on vaccination, neglecting the complex issues related to improving testing, diagnosis, contact tracing and clinical management of people with CHB. There is significant cultural and linguistic diversity among people with CHB in Australia; approximately 56% were born overseas, with Chinese and Vietnamese being the most common languages spoken by people with CHB.

Cultural understandings of CHB play a role in framing the meaning of the infection, particularly for people from culturally and linguistically diverse (CALD) communities. The impact of an inadequate diagnostic process means that people with CHB may have poor knowledge about transmission, implications of the infection and availability of treatment, which subsequently affects their engagement in ongoing clinical care.

Australia’s Second national hepatitis B strategy 2014–2017 set a target of diagnosing 80% of people living with CHB in Australia by 2017; current estimates indicate this will not be achieved. Primary care practitioners, namely general practitioners (GPs) and primary care nurses, are often tasked with the role of identifying risk factors for chronic disease and implementing best practice guidelines. However, in the case of hepatitis B, it has been reported that GPs have poor knowledge, specifically in interpreting hepatitis B serology results, and experience systematic barriers to testing people at risk of hepatitis B.

Australia’s National hepatitis B testing policy promotes confidential, voluntary testing with informed consent, and outlines the process for providing the test results. Testing and diagnosis are fundamental to reducing the burden associated with CHB, and are the cornerstone of Australia’s response to CHB. However, no formal dissemination or evaluation have ever been conducted to identify whether GPs and/or nurses are aware of, or systematically use, this policy.

Each Australian jurisdiction has developed a contact tracing procedure. These local procedures are primarily based on the recommendations of the Australasian contact tracing guidelines, which frame hepatitis B as a sexually transmissible infection (STI) or bloodborne...
virus (BBV) acquired in adulthood through sexual activity or sharing drug injecting equipment. While the guidelines emphasise the need to be attentive and sensitive to cultural diversity, there is no specific discussion of hepatitis B. The guidelines suggest household and sexual contacts of people with CHB should be traced back six months prior to the onset of acute symptoms, which is not relevant to hepatitis B infection acquired at birth.

At the population level, diagnosis of CHB followed by appropriate vaccination of at-risk contacts can effectively reduce transmission. At an individual level, an effective diagnosis is a critical step for a person to understand and reduce the impact of the infection. This study sought to understand the processes of testing, diagnosing and contact tracing from the perspective of people with CHB, GPs and nurses, to inform the development of effective health policy and Australia’s effort to increase the diagnosis rate of CHB in Australia.

**Methods**

Qualitative, semi-structured interviews were conducted with people who have CHB, and GPs and nurses who self-identified as having a high hepatitis B caseload, defined as at least one patient per month. Patient participants were from a range of rural, regional and urban communities across Australia. A convenience sample of people with CHB and primary care practitioners were recruited through community health centres, advocacy and support groups, and primary healthcare newsletters publicised to GPs and nurses.

Interviews with people who have CHB explored reasons for testing, who did the testing, what information was provided, and if and how they disclosed their infection to others. GPs and nurses were asked which patients they tested for hepatitis B and why; if and what types of pre-test and post-test information was provided; and how potential contacts were traced. All interview themes were based on previous research and policy recommendations from the National hepatitis B testing policy. The semi-structured design of the interview structures allowed the interviewer to follow concepts and themes as these presented.

Interviews with people who have CHB (n = 19) were conducted over the phone and face-to-face, and lasted between 20 and 40 minutes; seven interviews were conducted through an interpreter. Nineteen interviews, lasting approximately 20 minutes, were conducted with GPs and nurses over the phone, with one face-to-face interview.

All participants were reimbursed for their time, and consented to audio recording of the interview. The research gained ethics approval from La Trobe University’s Human Research Ethics Committee (reference number 14-034). Pseudonyms of participants have been used throughout.

Data analysis was based on a hybrid process of inductive and deductive thematic analysis involving theory-driven (ie based on the research questions and existing literature) and data-driven (ie themes drawn from data) coding. Data were managed in NVivo 10 and coded separately by two authors. This process of inter-rater reliability involved each reading and re-reading the data to identify emerging themes, and comparing these to achieve shared understanding and meaning of the data. Themes included emotional responses to diagnosis and cultural appropriateness of the testing process. Data were coded separately by two authors to ensure coding consistency using NVivo 10. All authors discussed the resulting themes.

**Results**

The findings describe experiences of testing, informed consent, being diagnosed and contact tracing from the perspectives of people with CHB, GPs and nurses.

**Demographics**

Nineteen people with CHB (male = 11; female = 8), 14 GPs (male = 8; female = 6) and five nurses (female = 5) were interviewed about hepatitis B testing. Patient participants with hepatitis B were broadly representative of the Australian cohort living with hepatitis B with regard to gender and country of birth. More male than female patient participants were recruited to this study, reflecting the higher prevalence of CHB among males. The patient participants’ country of birth reflects the cultural diversity of the hepatitis B epidemic globally, with 11 born in south-east Asia, the global region with the highest prevalence of CHB.

Table 1 provides demographic information for participants with CHB. Table 2 contains clinical and geographic characteristics for the primary care practitioners.

**Testing**

Patient participants with CHB reported being tested for the following reasons:
- Born in a high-prevalence country (n = 7)
- Routine blood donation testing (n = 4)
- Part of a general check-up (n = 2)
- Presenting with symptoms or feeling unwell (n = 4)
- Having a family or household member with CHB (n = 2).

Claudette, aged 18 years, immigrated to Australia from Sierra Leone, and asked her GP to conduct regular health monitoring. She was subsequently diagnosed with CHB.

*I went to my doctor and I told him I wanted to start having regular check-ups … and I did at first, and when I went for the results, he said I had hepatitis B.*

Arka, aged mid-30s, was one of two patient participants tested for hepatitis B in response to a family member being diagnosed with CHB:

*I had a blood test when I was about 18, and my doctor did a test for hepatitis … because my dad had it and he found out I was a carrier of hepatitis B.*

GPs and nurses based their decision to test patients for hepatitis B on the basis of their place of birth, risk factors (eg men who have sex with men, people who inject drugs, sex workers, or those training to be a medical professional),
symptomology, or whether they had a family member with CHB or liver problems.

I tend to risk profile people … anyone who is married to anyone from Asia or Africa – automatically high risk. If you received a blood transfusion in the past … and whether they’re immigrants.

– Peter, GP, Australian Capital Territory

GPs working in settings with a high caseload of refugees routinely tested patients for hepatitis B.

Most of the ones we see are newly arrived immigrants. They get the … standard refugee screening, which has it built in automatically. The other main ones we’d test would be people that we think are at risk because they’re relatives of people from the same community. – Joseph, GP, Victoria

Dash worked in a drug rehabilitation facility and tested all people who disclosed a history of drug injecting.

When we get a new patient … we just ask whether they know if they’re hepatitis B positive or not, whether they’ve had the vaccine.

– Dash, GP, New South Wales

Informed consent

The National hepatitis B testing policy states that ‘informed consent should be obtained for hepatitis B testing, except for rare occasions’, and that this process should include the ‘pre-test provision of all appropriate information’. Despite this, few patient participants reported being provided with information before testing or at the point of diagnosis. This resulted in many patient participants feeling shocked, with very little understanding about continued monitoring, transmission or whom they should inform. Ayana, aged mid-20s, who was diagnosed after the development of the testing policy, explained:

I didn’t have an understanding of [hepatitis B], either in my own culture and language (or) in English. And when he (GP) first saw me, he’s like, ‘Sorry, you’ve got hepatitis B’ … there was …

<table>
<thead>
<tr>
<th>Pseudonym and age</th>
<th>Children</th>
<th>Country of Birth</th>
<th>Time since first diagnosis (approximately)</th>
<th>Gender</th>
<th>Reason for testing</th>
<th>Relationship status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Akra, early 30s</td>
<td>No</td>
<td>Cambodia</td>
<td>10–15 years</td>
<td>Man</td>
<td>Family member with hepatitis B</td>
<td>De facto</td>
</tr>
<tr>
<td>Ayana, mid-20s</td>
<td>Yes</td>
<td>Somalia</td>
<td>8 years</td>
<td>Woman</td>
<td>Unwell</td>
<td>Married</td>
</tr>
<tr>
<td>Baw Mu Thaw, early 30s</td>
<td>No</td>
<td>Burma</td>
<td>4 years</td>
<td>Man</td>
<td>Refugee testing</td>
<td>Single</td>
</tr>
<tr>
<td>Brian, late 40s</td>
<td>Yes</td>
<td>Australia</td>
<td>30 years</td>
<td>Man</td>
<td>Family member with hepatitis B</td>
<td>Married</td>
</tr>
<tr>
<td>Carmi, early 70s</td>
<td>Yes</td>
<td>Philippines</td>
<td>5 years</td>
<td>Woman</td>
<td>Other illness</td>
<td>Married</td>
</tr>
<tr>
<td>Claudetta, aged 18 years</td>
<td>No</td>
<td>Sierra Leone</td>
<td>6 years</td>
<td>Woman</td>
<td>Unassigned</td>
<td>Single</td>
</tr>
<tr>
<td>Eh Soe, early 40s</td>
<td>Yes</td>
<td>Burma</td>
<td>3 years</td>
<td>Man</td>
<td>Blood donation</td>
<td>Married</td>
</tr>
<tr>
<td>Hser Eh, early 40s</td>
<td>Yes</td>
<td>Burma</td>
<td>1 year</td>
<td>Woman</td>
<td>Refugee testing</td>
<td>Married</td>
</tr>
<tr>
<td>Htoo Gay, mid-20s</td>
<td>Yes</td>
<td>Burma</td>
<td>8 years</td>
<td>Man</td>
<td>Family member with hepatitis B</td>
<td>Married</td>
</tr>
<tr>
<td>Kaw Moo, late 20s</td>
<td>No</td>
<td>Burma</td>
<td>1 year</td>
<td>Man</td>
<td>Refugee testing</td>
<td>De facto</td>
</tr>
<tr>
<td>Lah Doh, mid-20s</td>
<td>Yes</td>
<td>Burma</td>
<td>10 months</td>
<td>Man</td>
<td>Refugee testing</td>
<td>Divorced</td>
</tr>
<tr>
<td>Lena, mid-40s</td>
<td>Yes</td>
<td>Switzerland</td>
<td>30 years</td>
<td>Woman</td>
<td>Blood donation</td>
<td>Married</td>
</tr>
<tr>
<td>Long, early 40s</td>
<td>Yes</td>
<td>Thailand</td>
<td>10 years</td>
<td>Woman</td>
<td>General check up</td>
<td>Married</td>
</tr>
<tr>
<td>Madhav, early 30s</td>
<td>No</td>
<td>India</td>
<td>7 years</td>
<td>Man</td>
<td>Blood donation</td>
<td>Married</td>
</tr>
<tr>
<td>Malcolm, early 50s</td>
<td>Yes</td>
<td>Australia</td>
<td>25 years</td>
<td>Man</td>
<td>Unwell</td>
<td>Single</td>
</tr>
<tr>
<td>Paw Say Wah, early 20s</td>
<td>No</td>
<td>Burma</td>
<td>8 months</td>
<td>Woman</td>
<td>Refugee testing</td>
<td>Single</td>
</tr>
<tr>
<td>Rebecca, late 40s</td>
<td>No</td>
<td>Australia</td>
<td>16–25 years</td>
<td>Woman</td>
<td>Unwell</td>
<td>Single</td>
</tr>
<tr>
<td>Rodney, early 60s</td>
<td>No</td>
<td>Australia</td>
<td>26–50 years</td>
<td>Man</td>
<td>Unwell</td>
<td>Single</td>
</tr>
<tr>
<td>Tha Wah, mid-40s</td>
<td>Yes</td>
<td>Burma</td>
<td>26–50 years</td>
<td>Man</td>
<td>Refugee testing</td>
<td>Married</td>
</tr>
</tbody>
</table>
no discussion about it and what that meant for me. It was a bit of a shock, but I really didn’t understand it. Because of the complexity of CHB and the frequent low health literacy and English proficiency of many affected populations, one GP explained that he did not always provide much information before testing.

Most of the patients we see aren’t aware of the concept of bloodborne viruses and have very little health literacy. So we actually don’t provide them a lot of information before we test them. – Noah, GP, Victoria

**Being diagnosed**

Many patient participants reported being repeatedly diagnosed with CHB. The time since the patient participants’ first CHB diagnosis ranged from 10 months to 25 years. A large proportion of patient participants indicated that a lack of awareness about hepatitis B prior to their diagnosis meant they did not have the capacity to clarify what the diagnosis meant.

Before coming here I don’t know about hepatitis … so don’t know what to ask. – Lah Doh, aged mid-20s

I didn’t know much about the condition in the first place for me to … ask questions. – Mahdav, aged early 30s

For some patient participants, their lack of understanding was confounded by their GPs’ lack of concern about CHB. For Long, aged late-40s, being informed that she had CHB was shocking, and the lack of information provided to her had significant implications.

I’m really shocked and … I’m going to die earlier than another person because I got a liver problem and I will die in pain. But the doctor explain to me … I know you worry, you stress, but you cannot do anything.

Three patient participants received comprehensive information at diagnosis. Paw Say Wah, aged early 20s, noted the following.

They told me I have hep B and we may need to see you every six months to know the condition and when there is increase and decrease in the virus. – Paw Say Wah, aged early 20s

Hepatitis B diagnosis has social and clinical implications. Malcolm reflected that he would have appreciated receiving information about the risk of sexual transmission of hepatitis B because, without it, he ‘didn’t bother dating after [receiving the diagnosis]’. While Malcolm’s experience was more than 30 years ago, one young woman, diagnosed in 2014 was also concerned about establishing relationships.

[My GP] said it’s like [if I] have sex with anyone, I have to, you know, tell them because it’s an STD. – Claudette, aged 18 years

GPs provided varying levels of information to patients at the point of diagnosis. Joseph reported that ‘telling someone they have hep B is never a one-consult job’. Aamil, a GP from Western Australia

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**Table 2. Health professional participants**

<table>
<thead>
<tr>
<th>Current hepatitis B case load</th>
<th>State</th>
<th>General practitioner (GP)/primary care nurse</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aamil</td>
<td>&lt;1 per month</td>
<td>WA GP/primary care nurse</td>
<td>Man</td>
</tr>
<tr>
<td>Dash</td>
<td>High</td>
<td>NSW GP</td>
<td>Man</td>
</tr>
<tr>
<td>Feng</td>
<td>High</td>
<td>VIC GP</td>
<td>Man</td>
</tr>
<tr>
<td>Holly</td>
<td>High</td>
<td>QLD Primary care nurse</td>
<td>Woman</td>
</tr>
<tr>
<td>Jackie</td>
<td>High</td>
<td>VIC Primary care nurse</td>
<td>Woman</td>
</tr>
<tr>
<td>James</td>
<td>&lt;1 per month</td>
<td>VIC GP</td>
<td>Man</td>
</tr>
<tr>
<td>Jasmine</td>
<td>High</td>
<td>NT GP</td>
<td>Woman</td>
</tr>
<tr>
<td>Jenny</td>
<td>High</td>
<td>VIC Primary care nurse</td>
<td>Woman</td>
</tr>
<tr>
<td>Joseph</td>
<td>High</td>
<td>VIC GP</td>
<td>Man</td>
</tr>
<tr>
<td>Karen</td>
<td>Low</td>
<td>VIC GP</td>
<td>Woman</td>
</tr>
<tr>
<td>Laylah</td>
<td>&lt;1 per month</td>
<td>WA GP</td>
<td>Woman</td>
</tr>
<tr>
<td>Meg</td>
<td>High</td>
<td>VIC GP</td>
<td>Woman</td>
</tr>
<tr>
<td>Meka</td>
<td>Low</td>
<td>ACT GP</td>
<td>Woman</td>
</tr>
<tr>
<td>Noah</td>
<td>High</td>
<td>VIC GP</td>
<td>Man</td>
</tr>
<tr>
<td>Peter</td>
<td>Low</td>
<td>ACT GP</td>
<td>Man</td>
</tr>
<tr>
<td>Sarah</td>
<td>High</td>
<td>VIC Primary care nurse</td>
<td>Woman</td>
</tr>
<tr>
<td>Susanne</td>
<td>Medium</td>
<td>NSW GP</td>
<td>Woman</td>
</tr>
<tr>
<td>Tammy</td>
<td>Medium</td>
<td>NSW Primary care nurse</td>
<td>Woman</td>
</tr>
<tr>
<td>Thomas</td>
<td>High</td>
<td>VIC GP</td>
<td>Man</td>
</tr>
</tbody>
</table>
Contact tracing
Contact tracing seeks to reduce hepatitis B transmission and ensure that family, household and sexual contacts are tested and immunised. Patient participants with CHB described varying experiences of contact tracing, including an uncomplicated process of informing their close contacts about their diagnosis.

All family and friends. … I told them and they got tested. In my opinion, I think I should tell [them]. I can’t remember if doctor told me to tell them. – Tha Wah, aged mid-40s

The need to inform family members of a positive hepatitis B result can have significant implications, including multiple members of the family being diagnosed, some of whom live overseas.

My only brother who lives in LA is also hep-B positive … when I went home to the Philippines, my younger sister … found out she is also hep-B positive, which means three of us have been hep-b positive not knowing it – Carmi, aged early 70s

There was some confusion among GPs as to whether they, a specialist clinician, or the health department were responsible for contact tracing:
I don’t usually routinely do this … I’m not quite sure about that. – Dash, GP, New South Wales

For others, contact tracing was a standard part of their practice.

When they are diagnosed, I always advise the family, close family should get a check also. – Feng, GP, Victoria

Jenny, a nurse from Victoria described the systematic in-house procedure for contact tracing that had been developed by her organisation:
When [they see] me for the care plan, I print out the consent for the contact tracing. And then we put all the family members down … and the nurses all help me contact the … family members, if they need serology, etc. We’re picking up the new hep B patients that way.

The complexity of contact tracing was highlighted, particularly in the context of few resources.
Somali ethnicity in the UK reported that a lack of understanding of CHB was the major barrier to engagement in testing and contact tracing activities. It is critical that effective methods to support patients’ understanding of CHB (eg low health literacy resources, exploring the implications of infection) are developed and disseminated to primary care practitioners.

There is little clarity regarding the process of contact tracing and testing patients’ family, household and sexual contacts. Contact tracing practices used by GPs and nurses differed greatly, and there was confusion about whose responsibility it was to lead the process. Given that significant numbers of people with CHB in Australia are not engaged in regular clinical monitoring, developing a broader model of contact tracing is advisable. To implement a consistent approach to testing, diagnosis and contact tracing for other notifiable diseases, the Federal Department of Health, in consultation with the Communicable Diseases Network Australia (CDNA), has developed a series of national guidelines (SoNGs). At the time of publishing, a hepatitis B SoNG had not been developed to guide jurisdictional public health units in Australia on the process of testing and diagnosing hepatitis B.

Several nurse-led interventions have been implemented around Australia in an attempt to improve testing and diagnosis rates, and contact tracing. A report on a multidisciplinary approach, including primary care nurses, GPs and refugee health workers at one community health centre, describes the systematic tracing of family and household contacts (n = 420) of patients with CHB (n = 122). Most contacts were already immune, but around 12% were unprotected and 8% had CHB, demonstrating the role contact tracing can have in identifying undiagnosed people.

A significant limitation of the current contact tracing approach is the lack of differentiation between acute and chronic infection, with issues including the need for lifelong monitoring and disclosure not addressed. A model that moves away from an emphasis on acute or infectious disease to one that more forcefully addresses the personal, social and cultural issues that frame a hepatitis B diagnosis would have greater impact.

This research focused on GPs and nurses with a high caseload. Knowledge about the disease course, best practice around informed consent and need for contact tracing may be lower in the general population of primary care practitioners in Australia. This is a potential constraint of the research and should be taken into account when interpreting the results.

The National hepatitis B testing policy emphasises the need to provide culturally appropriate counselling and education during testing and diagnosis, and provides detail as to how GPs and nurses should execute this work. However, consideration of the structural issues (eg skills, time, communication) that might inhibit the implementation of culturally competent healthcare are not acknowledged. Future research needs to focus on trialling interventional strategies to support the implementation of the National hepatitis B testing policy in primary care, to improve the quality of the diagnostic experience for the patient, and to further explore the patient’s needs at the point of diagnosis.

**Authors**

Jacqueline Richmond PhD, MPH, BN, Research Fellow, Australian Research Centre in Sex, Health & Society, La Trobe University, Melbourne, Vic. J.Richmond@latrobe.edu.au

Elizabeth Smith PhD, BA (Hons), Research Fellow, Australian Research Centre in Sex, Health & Society, La Trobe University, Melbourne, Vic

Jack Wallace PhD candidate, MSoScC (IntDev), Research Fellow, Australian Research Centre in Sex, Health & Society, La Trobe University, Melbourne, Vic

Duane Duncan PhD, MA, BA (Hons), Research Fellow, Australian Research Centre in Sex, Health & Society, La Trobe University, Melbourne, Vic

Jayne Lucke PhD, BA (Hons), Director, Australian Research Centre in Sex, Health & Society, La Trobe University, Melbourne, Vic

Competing interests: None

Funding: The Australian Research Centre in Sex, Health and Society at La Trobe University receives funding from the Commonwealth Department of Health for a program of research in viral hepatitis related to the National STI/BBV Strategies.

Provenance and peer review: Not commissioned, externally peer reviewed.

**Acknowledgements**

The authors wish to acknowledge the participants in the study for sharing their experiences and the Federal Department of Health and Ageing who funded the project.

**References**


