

# Hepatitis B testing and diagnosis experiences of people with hepatitis B and health professionals

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# Background

- Chronic Hepatitis B (CHB) disproportionately affects people from culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander people
  - 44% have not been diagnosed
  - 87% of people with CHB are not receiving any clinical management<sup>1</sup>

<sup>1</sup> Allard NL, MacLachlan JH, Cowie BC. The cascade of care for Australians living with chronic hepatitis B: measuring access to diagnosis, management and treatment. Aust N Z J Public Health. 2015 Jun;39(3):255-9.



- No evaluation has been conducted to identify whether General Practitioners (GP) or practice nurses systematically use the policy

The screenshot shows the 'testing portal' website for ashm (Association of Sexual Health and HIV Specialists). The header includes the logo and the text 'Supporting the HIV, Viral Hepatitis and Sexual Health Workforce'. The navigation menu contains links for HOME, ABOUT, HIV, HEPATITIS B (highlighted), HEPATITIS C, HIV Rapid Testing, and LIBRARY, along with a search bar. The main content area is titled 'NATIONAL HBV TESTING POLICY' and includes a breadcrumb trail 'Home // Hepatitis B'. The text states that the policy is reviewed annually by the HBV Expert Reference Committee, with the 2015 review completed in March 2016, resulting in version 1.2. It provides links to the consultation process and the full policy document. A sidebar on the right offers a 'DOWNLOAD HBV TESTING POLICY' button and links to download the full policy (PDF) and view what's changed from the previous version. A table of contents on the left lists sections: 1.0 Introduction, 2.0 Diagnostic Strategies, and 3.0 Indications for HBV Testing.

HOME ABOUT ▾ HIV ▾ **HEPATITIS B ▾** HEPATITIS C ▾ HIV Rapid Testing LIBRARY

Home // Hepatitis B

## NATIONAL HBV TESTING POLICY

The National HBV Testing Policy is reviewed on a yearly basis by the HBV Expert Reference Committee.

The 2015 review was completed in March 2016 and resulted in the production of version 1.2.

Read more about the consultation process and Expert Reference Committee.

Download the full National HBV Testing Policy v1.2 or browse section by section and print only the sections you require.

- [1.0 Introduction](#)
- [2.0 Diagnostic Strategies](#)
- [3.0 Indications for HBV Testing](#)

**DOWNLOAD HBV TESTING POLICY**

Download the full [National HBV Testing Policy v1.2 \(PDF\)](#)

See [what's changed](#) from the previous version.

# Background

- Research suggests that people with CHB have limited understanding of their infection:
  - They receive little or no information at the point of diagnosis
  - Little understanding of the implications of being infected
  - Base their health care decisions on poor or inadequate information



# Aim of the study

- To explore the experiences of hepatitis B testing and diagnosis from the perspective of people with CHB, General Practitioners (GPs) and practice nurses.



# Methodology

- Qualitative semi-structured interviews were conducted over the phone and face-to-face with:
  - people with CHB (n=19)
    - 7 interviews were conducted with an interpreter
  - High case load GPs (> one patient per month) (n=15)
  - practice nurses (n=5)



# Results

- Hepatitis B testing was initiated by a health professional during routine screening:
  - blood donation (n=4)
  - general health check (n=2)
- OR presence of a risk factor such as:
  - country of birth (n=7)
  - Family/household member with CHB (n=2)
  - symptoms/feeling unwell (n=4).



## Results

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

(Claudette, 18 years old)





# Results

- GPs and practice nurses based their decision to test patients for hepatitis B on the basis of:
  - country of birth
  - cultural identity
  - family history of CHB or liver problems
  - experience of symptoms
  - identification with a priority population such as men who have sex with men, people who inject drugs, sex workers, or if they were entering a medical profession.



## Results

*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, ACT)



# Results

- National Hepatitis B Testing policy notes *“informed consent should be obtained for HBV testing, except for rare occasions”* and that this process should include the *“pre-test provision of all appropriate information”*
- Few participants with CHB reported being provided with information before testing or at the point of diagnosis



## Results

*I didn't have an understanding of it, 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." But, I wasn't expecting it so there was ... no discussion about it and what that meant for me. ... It was a bit of a shock, but I really didn't understand it.*

(Ayana, mid-20s)



## Results

*Most of the patients that we see aren't aware of the concept of blood-borne viruses and have very little health literacy. So we actually don't provide them a lot of information before we test them.*

(Noah, GP, VIC)



# Results

- Time since participants' first diagnosis ranged from 10 months to 25 years
- Participants lack of understanding about hepatitis B prior to diagnosis meant they had limited capacity to ask questions clarifying what the diagnosis meant



## Results

*Before coming here I don't know about hepatitis or disease so don't know what to ask.*

(Lah Doh, mid 20s)

*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.*

(Long, late 40s)



## Results

- Information provided by GPs at diagnosis varied
  - Most felt referral to a liver specialist was the most important aspect of diagnosis
  - Plain language explanations were critical so the patient understood the importance of referrals and continued monitoring
- Information about the virus, specifically the natural history was very important
  - Response consisted of providing a pamphlet or other written material





## Results

*...the main message is the importance of lifetime monitoring. We go over that again and again ... we might talk to them about who's going to follow them up, whether it's going to be me or a specialist, whether there's any chance that they might need treatment and so on ... telling someone they have hep B is never a one-consult job.*

(Joseph, GP, VIC)



## Results

- Lack of culturally appropriate resources:

*There hasn't been any particularly well thought out culturally appropriate educational programs for hepatitis B. ... They've done a lot on ear health and renal health and diabetes...*

(Holly, Nurse, QLD)



## Results

- Primary care nurses tended to become involved in hepatitis B patient after diagnosis:

*We usually get involved only once the ... positive result has come about...*

(Jackie, Nurse, VIC)

- Nursing role focuses on:
  - Developing care plans for people with CHB
  - Providing education on transmission and lifestyle



## Conclusion

- The National Hepatitis B Testing policy clearly outlines how hepatitis B should be tested and diagnosed
  - No participants reported being diagnosed in line with these expectations
  - No health professionals noted the testing policy as a resource informing their practice



# Conclusion

- Barriers to individuals participating in ongoing monitoring and surveillance:
  - Shock and stigma associated with diagnosis and hepatitis B
  - Lack of hepatitis B knowledge among primary health practitioners
- Building the capacity of individuals to participate in their chronic disease management is an important role of primary care



# Acknowledgements

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