

Communication and consent

The general principle is that patients are entitled to make their own decisions about testing and should be given adequate information on which to base their decisions (NHMRC, 2004:9).

HBV testing is routine but it involves considerable technical complexity and its recommendation for culturally diverse populations requires skills and strategies for cross-cultural communication.

One of the key strategies for avoiding information overload and communicating effectively across cultures is to slow down and space the provision of information over successive appointments.

For some patients— particularly newly arrived refugees from least developed countries with low English proficiency and little or no education – the amount and complexity of new information is simply too great, and they may take years to develop a working understanding of HBV. Informed consent in this situation means having an understanding adequate to make the decision to test.

Developing an understanding of the medical and psychosocial consequences of HBV infection is a separate and larger task (traditionally referred to as pre- and post-test counselling).

Sometimes the two can be done simultaneously and in other cases it is appropriate to separate them by staging the provision of information to avoid overloading the patient.

In choosing how to proceed, the clinician **should** use their judgment about the clinical need and relevant characteristics of the patient and the clinical interaction.

Continuity of care and the relationship between clinician and patient (as well as linkage into other supportive services) are in this situation of equal importance with patient autonomy as protected by the general principles of communicating information and informed consent.

Informed consent

Informed consent **must** be obtained prior to hepatitis B testing, no matter how routine, unless a legal order has been made for compulsory testing or another legal exception applies (such as an unconscious patient in an emergency setting). In cases where testing is legally mandated, pre-test information **should** still be provided.

What to communicate

Clinicians **should** be guided by the NHMRC *General Guidelines for Medical Practitioners on Providing Information to Patients* (NHMRC, 2004). [link]

The general guidelines include:

Information normally discussed (NHMRC General Guidelines, 2004)	Related to HBV testing in clinical settings
A. the possible or likely nature of the disease	<p>Clinician perspective Reason for testing Risk assessment Timing of any risk exposures Natural history of HBV and transmission routes Relevance of other BBV/STI tests (where adult risk factors are present)</p> <p>Patient perspective Key terms: hidden, asymptomatic, transmissible, long term, serious</p>
B. the proposed approach to investigation, diagnosis and treatment a. what the proposed approach entails b. the expected benefits c. common side effects and material risks of any intervention d. whether conventional or experimental e. who will undertake the intervention	Patient is aware they are being tested for HBV Basics of serology (test for virus and response) Confidentiality and privacy issues around testing General psychological state and social support assessments in the event of a positive result
C. other options for investigation, diagnosis and treatment	Option to delay testing and keep talking (stages of change approach)
D. the degree of uncertainty of any diagnosis arrived at	Explanation of window period Possibility of indeterminate test Need for further testing if positive
E. the degree of uncertainty about the therapeutic outcome	Implications of a positive test result Need for monitoring for treatment timing
F. the likely consequences of not choosing the proposed diagnostic procedure or treatment, or of not having any procedure or treatment at all	Impacts of chronic infection Natural history of HBV Prevention of transmission to third parties Need for vaccination if susceptible Option to delay or refuse testing (consent)
G. any significant long term physical, emotional, mental, social, sexual or other outcome which may be associated with a proposed intervention	Prevention of transmission to third parties Availability of vaccination if found to be susceptible and monitoring/treatment if positive Need for family screening if positive Rights to confidentiality and non-discrimination Reassurance of continuity of care and awareness of referral for specialist care if needed
H. the time involved	Implications of indeterminate test result Need for further appointments (time) Logistics of the testing process
I. the cost involved, including out of pocket costs.	Need for further appointments (cost) Free vaccine for household contacts Assessment of access to care (visa status)

Adapting communication to the patient

The way information is communicated should be adapted to the needs of the client (NHMRC 2004:12). Clinicians **should** use their judgment to decide how to communicate enough information for the patient to have an adequate understanding of HBV testing.

Scenario

You are conducting a refugee health check (including HBV testing) with a patient newly-arrived in Australia from a refugee camp in South-East Asia. The patient comes from a persecuted hill tribe in Burma, speaks no English, and cannot read or write in any language. His first experience of injection was forced vaccination by an army medic at the border. You must communicate, slowly, through an interpreter from a different ethnicity, speaking the language of the cultural group that oppressed the patient's own ethnic community in Burma. The language does not have words for basic concepts such as 'immune system', let alone 'antigen' or 'antibody'. In addition, the primary health belief system for the patient's cultural group is a mix of traditional and magico-spiritual beliefs; the pathogenic model of disease causation has not yet reached them. The patient feels overwhelmed by the battery of tests and many different appointments he must attend. Ninety days after arrival he will be required by Centrelink to enter English language classes or commence looking for a job.

In this scenario it would be appropriate to use simple language to communicate the possibility of infection with a hidden disease that can damage his health over a period of years and be passed on to family members. It would be appropriate to say the disease can be found in his blood and that a blood test can tell the doctor if it is present. If the disease is present, another test can help him decide if he needs a specific type of medicine from the doctor to protect his health, and the immigration department will not be told about it. If it is not present, three injections can be given to help his body recognise the disease and fight it off if he is exposed to it in future. He can choose not to have the test and he can also decide to wait and talk about it some more beforehand.

Other aspects of HBV testing and management **should** be explained over successive appointments, based on their relevance to his test results and the progression in his capacity to understand more at each point. At the same time, the patient **should** be given the choice to proceed, wait or decline the intervention, otherwise the clinician risks doing the same thing as the army medic at the border – teaching the patient that compliance and not consent is what matters in medical interactions.

Scenario

An elderly Chinese patient attends a GP of her own ethnicity for a general health checkup every year. She has seen a Cantonese-speaking GP in a busy single doctor practice for many years and they have a relationship of trust and respect. In a focus group about HBV knowledge she says she is sure he would have tested her for HBV if it was necessary and would not ask him specifically for it.

In some cultures doctors are accorded great respect and are expected to make decisions about what tests to order and how treatment should proceed. Patients may tacitly and quite willingly choose to let the doctor 'call the shots', placing the relationship of trust over and

above the expectation of autonomous decision-making by the patient envisioned by the principle of informed consent.

The NHMRC *General Guidelines* only allow this where the patient *expressly directs* the doctor to make the decisions, and states the doctor **should** still give the patient basic information about the illness and proposed intervention (NHMRC 2004: 12). Patients knowing their testing and vaccination history has both individual and community benefits, such as when they are invited to spread the word about hepatitis B prevalence among family and friends.

Communicating effectively through interpreters

At some point all clinicians are likely to encounter a patient with limited or no English proficiency. These patients are significantly more likely to return positive HBV serology (see Cowie, 2011, 'linguistic demography').

When providing a positive result for chronic HBV infection to patients with low English proficiency, clinicians **should/must** use an accredited interpreter. The Telephone Interpreter Service (TIS) is available without cost to doctors and has a high degree of acceptability to most clients, because it allows them to hide their identity.

Clinicians **should** take advantage of training opportunities in best practices for effective use of interpreters. Refer to the list of multicultural BBV agencies in the appendix or view the MHSS resource manual [link] Ch X on effective use of interpreters.