Perceptions of liver cancer and hepatitis B in the Victorian Chinese community
Summary Report 2013

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Cancer Council Victoria

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Executive summary

It is estimated that 218,000 people in Australia have chronic hepatitis B infection (CHB) with the majority having being born in the Asia Pacific region. Almost half of the people with CHB are undiagnosed, and up to one in four people will die from liver cancer.

Little is known about how the Chinese community would perceive and respond to messages that focus on encouraging them to test for hepatitis B in order to reduce the risk of liver cancer. Cancer Council Victoria (Cancer Council) undertook six focus groups with a total of 45 people to determine perceptions of this message, in particular whether promotion of the link between CHB and liver cancer would motivate or deter people from being tested.

The research identified some critical themes and observations including some of the following:

Motivators to testing and vaccination of hepatitis B

- The Chinese community would be expected to attend to messages about liver health, given the importance placed on the liver in Chinese medicine.
- Improving awareness of the link between hepatitis and liver cancer would influence motivation for testing.
- The perception that hepatitis B can be prevented with vaccination.
- Promotion of hepatitis B testing and vaccination needs to include a recognised health spokesperson within the Chinese community.

Barriers to testing and vaccination of hepatitis B

- The perception that the issue of hepatitis B was less problematic in Australia than in China.
- The perception that there is no treatment for chronic hepatitis B, and the belief that liver cancer has a poor prognosis and that treatment options are limited.
- A reliance on their GPs to inform them about it and to carry out any necessary tests.
- A perception that they would experience symptoms if they had chronic hepatitis, and an expectation that symptoms were the best indicator of the need for testing.
This research also illuminated some critical observations about the content and structure of messages relevant for future message development. These observations included:

- A message that includes the words “If you have hepatitis” strongly associates the statement with people who already know that they have the disease, and tells others that it is not personally relevant to them.

- A message about the absence of symptoms needs to be included in future communications. There was an expectation expressed by participants that symptoms would be the best indicator for testing.

- A message that focuses attention on the treatment of hepatitis B to prevent liver cancer will be more likely to be relevant for people who know they have chronic hepatitis B.

- Communications need to include a specific, blatant and detailed call to action. Many participants expressed a lack of clarity around whether they should be retested or revaccinated.
**Background**

Hepatitis B virus (HBV) is a major health burden with an estimated 360 million people living with chronic hepatitis B infection (CHB) worldwide.\(^1\) Australia has low (<2%), but increasing prevalence of CHB overall that affects an estimated 218,000 people.\(^2\) Almost half of these people are unaware they have chronic infection,\(^3\) and CHB is associated with long-term morbidity and mortality.

Improved testing and treatment for CHB in the culturally and linguistically diverse population has been cited as key priority areas in Australia’s first National Hepatitis B Strategy.\(^4\) Recent research indicates that appropriate treatment can reduce the risk of liver cancer by 50%. However, only 3% of those who require treatment are accessing it.\(^5\)

Primary liver cancer (most cases attributable to chronic viral hepatitis) has the fastest increasing cancer incidence, and is the fastest rising cause of cancer mortality.\(^6\) In Victoria the number of primary liver cancer cases has increased substantially with a tripling in the number of cases from 1982 to 2007.\(^7\) Most people diagnosed with liver cancer as a result of CHB present late in the course of disease and have poor outcomes.\(^8\)

CHB is an increasingly important long-term health issue in Australia, especially with the large number of migrants from the Asia-Pacific regions where the prevalence of infection is high. The Australian Chinese community has one of the highest prevalence rates of CHB and are up to 12 times more likely to develop liver cancer.\(^9,10\)

Recent Australian studies have identified that Chinese communities in Australia have low levels of understanding about how hepatitis B is transmitted, prevented and treated.\(^11,12\) Lack of awareness has also been associated with inadequate testing rates and poorer management outcomes.\(^13\) However, little is known about how Chinese communities understand the link between liver cancer and hepatitis B and how they would perceive and respond to liver cancer prevention messages that focus on encouraging them to test for CHB.
Awareness and communication campaigns have a pivotal role in enhancing understanding about hepatitis B and increasing testing rates with at-risk communities. An opportunity was identified to investigate a different health promotion approach within the Chinese community. A grant was provided by the Victorian Department of Health to investigate how key messages around the prevention of liver cancer would be received, rather than focusing on hepatitis B as the sole issue of concern.

This project undertook qualitative research with the Chinese community to investigate their perceptions of CHB and liver cancer, in particular whether promotion of the link between CHB and liver cancer would motivate or deter people from being tested for CHB.
Research approach

The Cancer Council commissioned Michael Murphy Research to conduct qualitative research to investigate the project based on the aims and objectives outlined below.

Research objectives

The overall aim of this research was to provide insights for the development of messages about chronic hepatitis B (CHB) that encourage behaviours to reduce the risk of liver cancer.

Specifically, the objectives of this project were:

• to identify perceptions of liver cancer and its link with CHB;
• to identify barriers and enablers to testing for CHB; and
• to determine perceptions of hepatitis B messages, in particular whether promotion of the link between CHB and liver cancer would motivate or deter people from being tested.

Phase 1: Exploratory interviews

Objectives for phase 1

To inform the development of focus group questions and group design in relation to:

• perceptions of CHB and liver cancer (risk, cause, outcome);
• the sensitivity of talking about CHB and liver cancer in a group situation, and;
• whether recruiting participants through existing social or sporting groups would inhibit discussion in focus groups.

Face-to-face interviews were planned with four participants, including one member of each of the four age/gender groups tabulated below. However, due to a cancellation, only three of these interviews could be completed prior to the groups. Interviews were conducted in homes of the participants.
Phase 2: Exploratory focus groups

Objectives for phase 2

- To identify perceptions of liver cancer and its link with CHB.
- To identify barriers and enablers to testing for CHB.

Four focus groups were conducted, with the sample segmented by age and gender, as documented in the table below. A total of 27 attended across the four groups (11 men and 16 women). Groups were conducted in Carlton and Preston.

Sample and segmentation

<table>
<thead>
<tr>
<th>Age</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>35–44</td>
<td>1 interview</td>
<td>1 interview</td>
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<tr>
<td></td>
<td>1 group</td>
<td>1 group</td>
</tr>
<tr>
<td>45–55</td>
<td>1 interview</td>
<td>1 group</td>
</tr>
</tbody>
</table>

Recruitment criteria included:

- Participants were aged between 35 and 55 years of age.
- Participants were born in mainland China.
- Participants were able to speak English well enough to participate in a group discussion. Please note, that although this criteria was specified at the time of recruitment, it became evident that several of the group members spoke little English. The groups were conducted in a mix of Mandarin and English. The group moderator was limited to English, an assistant spoke Mandarin.
- Participants were excluded if they had student visas.

Prior to the focus groups, participants were asked if they had ever been tested for hepatitis B. This was to limit the number of people in the groups that had been tested (and were therefore less likely to be able to talk about barriers to testing). Participants were not asked to disclose their hepatitis B status.

These age groups were chosen for two reasons. Firstly, to reach people who may have CHB and need immediate diagnosis to ensure they are able to access timely treatment and monitoring that will reduce their risk of liver cancer. Secondly, it was to retain some homogeneity within the groups (for example, the needs and experiences of young people without families could vary greatly from those who were older and have had children).
Phase 3: Assessment of draft messages

Objectives for phase 3

- To assess nine draft messages that have been developed for an education and awareness campaign in terms of clarity, cultural appropriateness, usability of the information and potential influence.

Two focus group discussions were conducted, with two groups segmented by sex. A total of 15 participants (7 women, 8 men) took part in the research. Participation criteria were the same as for Phase 1 and 2 listed previously.

As some of the group members could speak little English, the groups were conducted in a mix of Mandarin and English. The group moderator was limited to English, and an interpreter who was fluent in both English and Mandarin translated questions and answers as necessary. The groups were conducted in Carlton.

The draft messages assessed in this phase are listed in Appendix 1.

Recruitment

For each phase, recruitment was conducted through a range of methods. A professional recruitment agency recruited participants for the interviews. Cultural Intelligence was also engaged to specifically recruit participants for the focus groups. Recruitment was conducted via Chinese radio promotions and contacts within Chinese community groups. Participants were paid an incentive according to current market rates.

Ethics

This research was approved for an exemption from formal review by the Human Research Ethics Committee at Cancer Council Victoria.
Analysis and reporting

A thematic analysis was conducted for each phase. This analysis was based on a combination of notes taken during the groups and a review of the recordings of the group discussions. As the groups were conducted in a mix of English and Mandarin, they were not verbatim transcribed. Hence the quotes included in this report should not be regarded as verbatim.
Overview of findings

The following section provides a summary of the key findings and themes identified during the three research phases.

Phase 1 and 2: Exploration of understanding and perceptions of hepatitis B and liver cancer

Phase 1 and 2 explored participants’ understandings and perceptions. Key findings from these stages of exploratory research include:

Awareness of liver cancer

- The liver was acknowledged as a critical organ from a Chinese medicine perspective, and for this reason people within the Chinese community would be expected to be receptive to messages about liver health.
- The understanding of the liver as a critical organ seemed to have resulted in a reasonable level of awareness and understanding of liver-related diseases, such as liver cancer, cirrhosis and hepatitis.
- There was some awareness that liver cancer was an issue within the Chinese community.

Perceptions of causes of liver cancer

- Alcohol was seen as the primary cause of liver disease generally, and of liver cancer specifically.
- Diet was listed, and there was a sense that liver cancer was a disease of “the wealthy”, those who eat too much fat and rich foods.
- It was common amongst both the men and the women to report that liver problems were associated with emotional imbalances.
- Hepatitis was mentioned in each group as being associated with liver cancer, although specific knowledge of the link was neither universal nor especially detailed.

Hep B become liver cirrhosis … liver cirrhosis become liver cancer.

Smoking bad for liver. Many Chinese smoke, drink alcohol.
Perceptions of treatment and prognosis for liver cancer

- There was a general sense that liver cancer prognosis was quite poor. For some this was based on what they had learned through close associations (family, friends) who had been diagnosed with the disease.
- Related to this, there was a general belief that treatment of cancer was limited, and that a diagnosis was terminal.

> No cure, only morphine injection to take away the pain.

Hepatitis B awareness

- Hepatitis B was recognised as a common disease amongst the Chinese community. However, this is considered to be more of an issue for people in China, than for those who have moved to Australia. In some groups, participants mentioned that they had heard that infection rates were 10% or more amongst the Chinese population.
- Given this high awareness and the belief that hepatitis B was quite common, there was a sense that the disease was almost normal. Several participants indicated that it would not be a surprise to hear of a friend or family member receiving a hepatitis B diagnosis. Given this sense of hepatitis B being normal and common, it was also not regarded as especially serious.
- The common perception was that hepatitis B is transmitted through the sharing of food and eating implements. Given that this practice is more strongly associated with Chinese culture, this is considered more of a concern for those in China than for those who have moved to Australia.
- Despite this reasonably good awareness of hepatitis, specific knowledge of hepatitis tended to be somewhat generic. For example, while participants understood that there were different types of hepatitis, they were commonly unsure of the difference between them in terms of transmission, treatment and seriousness.
- Related, there was a lack of clarity about whether hepatitis B could be treated. Some felt that it could, while others believed that there was no treatment. Amongst some of the latter group, this perception resulted in a belief that there was little point being tested or diagnosed, as there was nothing that could be done to treat the disease.
Perceived cause of hepatitis B

- There was a general understanding that hepatitis was an infectious disease that could be passed from one person to another. However, specific knowledge of the mode of transmission and, as noted above, of the different types of hepatitis, was less common.

- Hepatitis B amongst the Chinese community was regarded as being most commonly transmitted through sharing of food and eating utensils. Participants talked about the common practice of shared food bowls, and believed that this was the reason that hepatitis B was so common amongst the Chinese community. From this perspective, hepatitis B was understood to be transmitted through saliva.

- There was some understanding that hepatitis B could also be transmitted through other body fluids (blood, sexual fluids, perinatal). However, this knowledge was not universal, and these forms of transmission were regarded as much less common.

  *Infected by others … chopsticks use a problem, someone pick up dishes from one bowl, and put in your bowl.*

Perceptions of stigma associated with hepatitis

- Overall, the issue of stigma associated with hepatitis B was somewhat unclear. Participants typically commented that there was no such stigma. However, they also reported being unsure about whether they would tell others if they had been diagnosed with hepatitis B, and discussed the difficulties and complications that were faced when someone was known to have hepatitis B.

- The stigma associated with hepatitis B was more related to concerns about passing it on than about how one might have been infected. Transmission through blood and sexual fluids were not top of mind, and there was little association of hepatitis B with other diseases that were transmitted this way. Hence, the stigma was limited.

- However, perceived complications were related to how someone with hepatitis B would be treated if they were to visit a home of a friend or family member. There was a concern about how a person with hepatitis B should be treated in social contexts that involve the sharing of food. Some commented that they might not tell others for this reason and others reported that they would probably prefer not to eat in a social context for this reason.
Within the interviews and groups, participants consistently reported that there was no obvious factor that would prevent them from discussing the topic of hepatitis B amongst family members, or in these group discussions.

**Association between hepatitis B and liver cancer**

- There was some understanding that hepatitis B could lead to chronic liver problems such as cirrhosis, and that this was the possible link with liver cancer. However, it was also apparent that there was limited knowledge regarding how hepatitis B was linked with liver cancer.

**Testing and vaccinations**

- Some reported that they had been tested for hepatitis B previously. However, it was also apparent that some were not sure whether they had been tested.
- Some mentioned that they had been tested before immigrating to Australia.
- Some reported having been vaccinated (in China). In general, there was a lack of knowledge about how long the vaccination lasted, and whether it would need to be repeated.
- Given the perception that the primary form of transmission was through sharing food, some felt that hepatitis B was not as much of a problem when living in Australia. Hence, they felt that there was less of a need to continue being tested once they were here.
- Differences between the Chinese and Australian health systems, and lack of familiarity with the local system appear to contribute to lower rates of attendance at GPs and therefore to hepatitis B testing. It was reasonably common for participants to report that they have regular check-ups when they go back to China. The tendency to leave health checks until they returned to China was especially common amongst the more recent arrivals.
- Amongst those who attended a GP in Australia, there was no reason not to test, they simply believed that the prompt should come from the GP.
Communication preferences

- During the groups, participants consistently reported that if they were provided with more information about hepatitis B and its link with liver cancer, they would be more likely to be tested and / or vaccinated.

- There was a tendency to prefer communications to be directly targeted at the Chinese community (including radio, newspapers and a familiar spokesperson).

Phase 3: Assessment of draft messages

“If the data is so strong, that means for the whole Chinese community that it is an important thing. These messages very important and probably need to do more about it.”

The specific aim of this stage was to assess draft messages that could be used in awareness campaigns aimed at the Chinese community in terms of clarity, cultural appropriateness, usability of the information and potential influence.

This phase confirmed two of the key themes that emerged in the exploratory stages. Participants again placed value upon the liver as a critical organ. Participants also showed an awareness that chronic hepatitis B was common in the Chinese community, and some also understood it could lead to liver cancer.

The sample of participants for this stage included people who had lived in Australia for a considerable length of time (by comparison, the exploratory research groups included some who had arrived in the last year). Hence, a couple of findings from the earlier research were not supported in this stage, although they may be salient for Chinese people who are more recent arrivals. These findings included:

- Participants in this third phase were quite familiar with the Australian medical system, including the protocols for attending GPs and cost issues. Hence lack of familiarity was not a barrier to testing.

- Related to this, these participants reported being unlikely to return to China for any kind of medical procedure.

Focus testing the draft messages provided crucial insights into what components of a message were most influential in terms of prompting people to be tested for hepatitis B (refer to Appendix 1 for the list of messages). The following information or concepts were found to be most motivational:
• **Hepatitis B is more prevalent in the Australian Chinese community** than the Australian population. The value of this information is that it made hepatitis a personal and pertinent issue for the Chinese community and something that they need to take notice of.

• That **a high proportion of people with hepatitis B go on to develop liver cancer**, and that this proportion is more prevalent in the Australian Chinese community than in the Australian population. The statistical information in messages 4 and 5 portrayed a sense of severity or threat and this style of information had the strongest impact of all of the messages.

• A statement about the **prevention of hepatitis B with vaccination** is of higher importance for those participants who believed they didn’t have hepatitis, than a statement about anti-viral treatment for chronic hepatitis B.

• **Referring to the importance for the whole family** will generate attention and motivate testing (focusing on the family creates an emotional narrative).

This phase of the research also illuminated some critical observations about the content and structure of the messages (relevant for future message development). These observations included:

• A message that includes the words “If you have hepatitis” strongly associates the statement with people who already know that they have the disease, and tells others that it is not personally relevant to them.

• A message about the absence of symptoms needs to be included in future communications. There was an expectation expressed by participants that symptoms would be the best indicator for testing.

• A message that focuses attention on the treatment of hepatitis B to prevent liver cancer will be more likely to be relevant for people who know they have chronic hepatitis B.

• Communications need to include a **specific, blatant and detailed call to action.** Many participants expressed a lack of clarity around whether they should be retested or revaccinated.
In summary, this research has provided critical insights that are of value to the development of culturally responsive communication and awareness campaigns for the Chinese community. The findings show support for the promotion of messages that focus on the link between hepatitis B and liver cancer as a way of encouraging the Chinese community to test for hepatitis B to reduce the risk of liver cancer. There are limitations to the generalisability of the Victorian based findings to the Australian Chinese community. However, this research is unique in that it is the first exploratory study to investigate the perceptions of hepatitis B and its link to liver cancer in detail with a community highly affected by hepatitis B and liver cancer.
Summary of research findings

The main motivators to testing and vaccination of hepatitis B include:

- The Chinese community would be expected to attend to messages about liver health, given the importance placed on the liver in Chinese medicine.
- Improving awareness of the link between hepatitis and liver cancer would influence motivation for testing.
- The perception that hepatitis B can be prevented with vaccination.
- Increasing understanding that there are treatments for hepatitis B that can reduce the chance of liver cancer.
- Promotion of hepatitis B testing and vaccination needs to include a recognised health spokesperson within the Chinese community.

The main barriers to testing and vaccination of hepatitis B include:

- The perception that the issue of hepatitis B was less problematic in Australia than in China. Associated with this was a perception that hepatitis B is associated with lifestyle factors (diet, hygiene, stress), and that these are not as problematic for Chinese people living in Australia as those in China.
- The perception that there was no treatment for hepatitis B, and the belief that liver cancer has a poor prognosis and that treatment options are limited.
- A lack of familiarity with the Australian health system for newer arrivals.
- A reliance on their GPs to inform them about, and to carry out, any necessary tests. Associated with this, there was a perception that if the issue was important, the tests might already be included in their regular regime of check-ups.
- A perception that they would experience symptoms if they had hepatitis, and an expectation that symptoms were the best indicator of the need for testing.
- A lack of clarity around whether previous tests and vaccinations were sufficient.
Recommendations for awareness campaigns and communication designs

- Communications need to increase **awareness of the link between hepatitis B and liver cancer**.

- A strategy to encourage testing for hepatitis B amongst the Chinese community will need to include a focus on the message being provided by GPs.

- Communications need to include **a specific, blatant and detailed call to action** (enables confidence or belief in the required action).
Future directions and recommendations

In working towards liver cancer prevention in affected communities, Cancer Council Victoria, and other interested agencies should:

1. Use liver cancer prevention messages in communication and awareness campaigns to increase the diagnosis and management of chronic hepatitis B in Chinese communities.

2. Continue to identify and implement strategies that enable GPs to appropriately test and manage people most at risk of developing liver cancer from chronic hepatitis B. These include but are not limited to:
   a) researching and advocating for systems and procedures that enhance clinical practice;
   b) in partnership, provide education to increase understanding about the prevention of hepatitis B related liver cancer;
   c) implementing media and communication campaigns to increase their understanding of the link between hepatitis B and liver cancer.

3. Pursue funding to investigate perceptions of liver cancer and hepatitis B in other at risk communities (e.g. Vietnamese and Aboriginal and Torres Strait Islander communities), to identify:
   a) the barriers and enablers to hepatitis B testing;
   b) the barriers and enablers to hepatitis B monitoring and liver cancer screening for people who have chronic hepatitis B.

4. Support and advise other organisations to integrate liver cancer prevention messages into health promotion initiatives related to hepatitis B.

5. Continue and enhance collaborations with community groups and peak organisations representing culturally and linguistically diverse groups to ensure affected communities can be actively involved in the public health response to hepatitis B and liver cancer prevention.
Appendix 1

Draft messages developed for testing

1. Chronic infection with hepatitis B is a common cause of liver cancer for people born in China and for Chinese Australians.

2. Look after your liver: if you know you have hepatitis B you can reduce your risk of liver cancer.

3. It is important for you and your family to get tested for hepatitis B to prevent liver cancer.

4. Chronic hepatitis B infection can lead to liver damage and liver cancer.
   70–80% of liver cancers caused by hepatitis B infection are in Asian people living in Australia.

5. People born in China and other Asian countries are up to 12 times more likely to get liver cancer.

6. If you have hepatitis B, you can prevent liver cancer with regular check-ups and medication. If you don’t have hepatitis B, you can get vaccinated and this will protect you.

7. Don’t wait for symptoms, get tested for hepatitis B and find out what steps you can take to prevent liver cancer. Hepatitis B can be treated with medications to prevent liver cancer.

8. Don’t wait to go back home to China. See a doctor and get tested and treated for hepatitis B.

9. If your doctor bulk bills, your visit is free because Medicare pays the doctor. If your doctor does not bulk bill, you pay the doctor first and they you claim some money back from Medicare.
References


