

1

2 DR. JACK WALLACE (Orcid ID : 0000-0002-4738-7316)

3 PROF. MARGARET HELLARD (Orcid ID : 0000-0002-5055-3266)

4 DR. TIMOTHY J PAPALUCA (Orcid ID : 0000-0003-0296-8624)

5

6

7 Article type : Original Article

8

9

10 **A qualitative exploration of enablers for hepatitis B clinical management among**  
11 **ethnic Chinese in Australia**

12 Enablers for attending hepatitis B clinical management (running title)

13 Yinzong Xiao<sup>1,2,3\*</sup>, Jack Wallace<sup>1,4\*</sup>, Alex Thompson<sup>2,3</sup>, Margaret Hellard<sup>1,3,5,6,7</sup>, Caroline van Gemert<sup>1,3</sup>,  
14 Jacinta A Holmes<sup>2</sup>, Catherine Croagh<sup>2</sup>, Jacqui Richmond<sup>1</sup>, Tim Papaluca<sup>2,3</sup>, Samuel Hall<sup>2,3</sup>, Thai Hong<sup>2</sup>,  
15 Barbara Demediuk<sup>2</sup>, David Iser<sup>2</sup>, Marno Ryan<sup>2</sup>, Paul Desmond<sup>2</sup>, Kumar Visvanathan<sup>2</sup>, Jess  
16 Howell<sup>1,2,3,5†</sup>

17 1. Burnet Institute, Melbourne 3004, Victoria, Australia

18 2. Department of Gastroenterology, St Vincent's Hospital, Fitzroy 3065, Victoria, Australia

19 3. University of Melbourne, Parkville 3010, Victoria, Australia

20 4. La Trobe University, Bundoora 3086, Victoria, Australia

21 5. School of Public Health and Preventive Medicine, Monash University, Melbourne 3004, Victoria,  
22 Australia23 6. Department of Infectious Diseases, The Alfred and Monash University, Melbourne 3004,  
24 Victoria, Australia

25 7. The Peter Doherty Institute for Infection and Immunity, Melbourne 3000, Victoria, Australia.

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/JVH.13495](https://doi.org/10.1111/JVH.13495)

This article is protected by copyright. All rights reserved

26

27 *\*these authors contributed equally to this work*

28 †*Corresponding author; email: jess.howell@burnet.edu.au*

29

30

### 31 **Acknowledgements**

32 Many thanks to all participants with lived experience and their families, who generously  
33 shared their time and stories with us. Thank you to the doctors, nurses, receptionists, and  
34 interpreters within the liver clinics at St Vincent's Hospital (Melbourne) who supported our  
35 study. Thank you also to Dr Lucy Lim and Dr Elliot Freeman who supported our recruitment.  
36 JH, AJT, CvG, JW and MH receive fellowship support from the Australian National Health and  
37 Medical Research Council. YX is supported by the Melbourne Research Scholarship. JH is  
38 supported by a University of Melbourne Faculty Trust Fellowship.

### 39 **Data availability statement**

40 The data that support the findings of this study are available on request from the  
41 corresponding author. The data are not publicly available due to ethical restrictions.

### 42 **Abstract**

43 An estimated 18% of people living with chronic hepatitis B (CHB) in Australia were born in  
44 China. While guideline-based care, including regular clinical monitoring and timely  
45 treatment, prevent CHB-related cirrhosis, cancer and deaths, over three-quarters of people  
46 with CHB do not receive guideline-based care in Australia. This qualitative study aimed to  
47 identify enablers to engagement in CHB clinical management among ethnic Chinese people  
48 attending specialist care. Participants self-identified as of Chinese ethnicity and who  
49 attended specialist care for CHB clinical management were interviewed in Melbourne in  
50 2019 (n=30). Semi-structured interviews covered experiences of diagnosis and engagement  
51 in clinical management services, and advice for people living with CHB. Interviews were  
52 recorded with consent; data were transcribed verbatim and thematically analysed.  
53 Receiving clear information about the availability of treatment and/or the necessity of long-  
54 term clinical management were the main enablers for participants to engage in CHB clinical

55 management. Additional enablers identified to maintain regular clinical monitoring included  
56 understanding CHB increases risks of cirrhosis and liver cancer, using viral load indicators to  
57 visualise disease status in patient-doctor communication; expectations from family, peer  
58 group and medical professionals; use of a patient recall system; availability of interpreters  
59 or multilingual doctors; and largely subsidised healthcare services. In conclusion, to support  
60 people attending clinical management for CHB, a holistic response from community,  
61 healthcare providers and the public health sector is required. There are needs for public  
62 health programs directed to communicate i) CHB-related complications; ii) availability of  
63 effective and cheap treatment; and that iii) long-term engagement with clinical  
64 management and its benefits.

#### 65 **Key words**

66 Hepatitis B, hepatitis B clinical management, Chinese, qualitative

#### 67 **Introduction**

68 Hepatitis B causes around 50% of liver cancer cases worldwide, with an estimated 786,000  
69 deaths each year<sup>1,2</sup>. In 2016, the World Health Organization set the goal of eliminating viral  
70 hepatitis as a public health threat by 2030<sup>3</sup>. A key priority for elimination is increasing the  
71 number of people with chronic hepatitis B (CHB) receiving guideline-based clinical  
72 management.

73 CHB clinical management, provided by specialist clinicians or authorised general  
74 practitioners in Australia, includes regular blood tests to assess for evidence of liver  
75 damage<sup>4,5</sup>. For people not eligible for treatment, regular monitoring ensures the timely  
76 commencement of treatment to prevent cirrhosis and reduce risks of CHB-related liver  
77 cancer. Among those on treatment, regular monitoring with blood tests is also required to  
78 determine treatment response. Additionally, people with CHB who are eligible for liver  
79 cancer surveillance require a liver ultrasound every six months to detect liver cancer at an  
80 early stage when curative treatment can still be offered<sup>4,5</sup>.

81 Among all people living with CHB in Australia in 2018, only 22% were being clinically  
82 managed with less than 10% being treated (i.e. approximately one-third of those requiring

83 treatment) <sup>6</sup>. In 2018, the Australian government set national targets of 80% of people with  
84 CHB being diagnosed, 50% engaging in clinical management and 20% receiving anti-viral  
85 treatment by 2022<sup>7</sup>. To achieve these targets, interventions are needed to support at-risk  
86 populations to be tested and people diagnosed with CHB to be linked to and stay in clinical  
87 management services.

88 People from culturally and linguistically diverse (CALD) communities are disproportionately  
89 represented among people with CHB in Australia: an estimated 61% of people living in  
90 Australia with CHB were born overseas, with the most common country of birth being  
91 mainland China<sup>8</sup>. Several barriers to hepatitis B testing and linkage to care have been  
92 reported for people from CALD communities including lack of symptoms, low hepatitis B-  
93 related knowledge, language barriers, low health literacy and cultural beliefs <sup>9-12</sup>. In  
94 addition, hepatitis B-related stigma and/or fear of being stigmatised, as well as the fear of  
95 social implications such as being rejected for jobs or residency applications due to CHB,  
96 further impede people from being engaged in CHB clinical management <sup>13, 14</sup>. In response,  
97 programs have been developed to engage people with CHB in care including outreach  
98 campaigns, community or health facility-based educational activities and screening  
99 programs <sup>15-17</sup>. However, research to date has primarily focused on increasing hepatitis B  
100 testing and treatment uptake, with limited evidence identifying how to support infected  
101 individuals attend and stay engaged in regular clinical management, especially those not  
102 currently receiving treatment based on clinical guidelines<sup>4, 5</sup>.

103 To identify the factors supporting people to engage with and be retained in CHB clinical  
104 management, we conducted qualitative semi-structured interviews with people who self-  
105 identified as ethnic Chinese attending tertiary care regularly for CHB. We sought  
106 information on their understanding, experiences, and perspectives of living with CHB and  
107 attending clinical management, and any suggestions the study participants had for other  
108 people living with CHB. Here, we report findings on enablers to attend clinical management  
109 for CHB.

## 110 **Methods**

### 111 Design, setting and sampling methods

112 The descriptive qualitative study was conducted in a specialist liver clinic in a public hospital  
113 in Melbourne between 1st September to 30th November 2019. The sample were adults who  
114 self-identified as being of Chinese ethnicity who accessed health services for CHB clinical  
115 management and where we could explore the enablers for attending regular CHB clinical  
116 management. The sample is limited to those patients who actively engaged in specialist care  
117 for CHB clinical management through this health service. Sample size was determined when  
118 reaching data saturation, that is, when no new data found from last few interviews. The  
119 study was approved by the Human Research Ethic Committees of Alfred Health and St  
120 Vincent's Hospital Melbourne.

### 121 Participant recruitment

122 Individuals attending liver clinic appointments during the study period were assessed for  
123 eligibility by a member of the research team based on medical records (YX); eligible  
124 individuals were given a brief introduction of the study by their doctors and invited to  
125 participate. The number of people invited by their clinicians were not recorded. Individuals  
126 who were interested in participating were recommended to study investigators, JW and YX,  
127 who were public health researchers and do not provide clinical care. JW is a male researcher  
128 with a PhD who has led multiple qualitative studies involving different ethnic groups living  
129 with CHB; YX is a female PhD student doing public health research training and speaks  
130 Mandarin as first language, and neither had any relationship with potential participants  
131 prior to the study. As part of the informed consent process, an investigator (JW or YX) spoke  
132 with potential participants about the investigators' roles, study procedures, questions to be  
133 asked, and reassured participants that they could choose not to answer questions and were  
134 free to withdraw from the study at any time, and that the interviews were confidential, and  
135 that study participation or refusal would not affect their medical care.

### 136 Data collection

137 All individuals referred to study investigators (n=30) consented and interviewed by one  
138 investigator (JW or YX) in a private room at the study site (n=28) or via scheduled phone call

139 (n=2). Three participants from the same family were interviewed together; five participants  
140 had their family member(s) present as non-participants.

141 Participants were asked questions following the interview guide (Supplementary Table s1),  
142 which was developed based on previous literature and relevance to the research question.  
143 Topics included in this analysis included 1) experiences of diagnosis; 2) journey of (not)  
144 attending clinical care after diagnosis; 3) experiences and perspectives of attending CHB  
145 clinical care in Australia.

146 Interviews ranged between 15-30 minutes, were conducted in Mandarin or English as per  
147 participants' preferred language. Interviews were electronically audio recorded with  
148 participant consent; where participants consented to participate in the study but refused to  
149 be recorded, notes were taken during interview (n=1).

#### 150 Data analyses

151 All recordings were transcribed verbatim in English or simplified Chinese (by JW or YX);  
152 transcripts in Chinese were translated to English, and transcripts and interview notes were  
153 imported into QRS NVivo 12 for coding. Thematic analysis<sup>18</sup> was used to guide coding: all  
154 transcripts were coded independently by JW and YX, codes were compared and discussed  
155 weekly, any discrepancies were discussed with a third investigator (JH). An agreed analytical  
156 framework containing grouped codes were developed and subsequently applied to all  
157 transcripts to characterise the elements affecting participants' attendance for CHB clinical  
158 management. The Health Belief Model<sup>19</sup> guided the analysis given its relevance to the  
159 research including the aim and analysing and its utility in intervention development<sup>20</sup>.

#### 160 **Results**

161 Twenty-eight interviews were conducted with 30 participants. Demographic characteristics  
162 of participants are in *Table 1*.

#### 163 Linking to clinical care

164 Twenty-three participants (76%) reported being diagnosed at 25 years of age or younger;  
165 twenty-one participants (70%) had CHB first diagnosed outside Australia, with people born  
166 in Mainland China and Malaysia mostly diagnosed in their country of origin (*Supplementary*

167 Table s2). Following diagnosis of CHB, ten reported delayed engagement in CHB clinical  
168 management (that is, not attended clinical management for CHB at least once a year<sup>4, 5</sup>),  
169 including seven who were first diagnosed overseas, and three first diagnosed in Australia.

170 A common reason for this delay in accessing clinical management for their CHB was advice  
171 they reported receiving when diagnosed: that there was no effective treatment, which was  
172 further interpreted as no further action was required by the patient.

173 *When I found out, I went to see the GP, more than twenty years ago...none of the*  
174 *treatment...nothing I can do, just sit down and when the God call me, and I'll go with*  
175 *the God, that's it (laugh) (Participant 16, male, 63y)*

176 Sometimes, the fact that no treatment was offered, or the advice that no treatment was  
177 needed, was interpreted as no further engagement with a clinical service was needed.

178 *The doctor didn't say that I needed to use medicine to control, he just told me, you*  
179 *are a carrier. Well, (he) didn't talk about routine check-ups or things like that.*  
180 *(Participant 27, female, 38y)*

181 *My GP was very relaxed, she told me 'oh it might go away if your immune system is*  
182 *strong'. (Participant 20, female, 50y)*

183 Inadequate, little or no information received upon diagnosis, especially when individuals  
184 were diagnosed outside a health facility (usually in a school or work-based screening  
185 program) at a young age, was another reason for people disengaging from clinical  
186 management.

187 *No (information was provided upon receiving my testing results). I didn't know much*  
188 *about hepatitis...when I was 18 or 19 years old, I didn't care. (Participant 14, male,*  
189 *43y)*

190 For participants with delayed linkage to CHB clinical management, specific events brought  
191 them back to clinical management in a passive way, such as experiencing symptoms or  
192 having abnormal testing results that later led to referral to tertiary care.

193 *About three years ago, I felt very tired, by accident too, my stomach was inflaming...*  
194 *It was so severe so next day I went to see a doctor... they found out that the virus*

195 count was really high. So she started to send me here (to see specialist). (Participant  
196 7, male, 53y)

197 I didn't take it serious previously. When I was travelling in China last year, (it) might  
198 (be) due to exhaustion from long travel, I started to become ill and ended up going to  
199 the ER. (Participant 2, female, 35y)

200 Discovering that treatment for CHB was available motivated several participants to actively  
201 engage in CHB clinical management. Usually participants were told about CHB treatment  
202 from their primary care doctor and then referred to tertiary care.

203 After a few years, accidentally I went to see one of the family doctors, Dr. H, and he  
204 said, oh now the hospital got the treatment, do you want to go to see the specialist?  
205 (Participant 16, male, 63y)

206 When we were in China, I didn't hear of any treatment. So there was a time I had my  
207 regular health check-ups here (at my GP in Australia), they told me (that I had  
208 hepatitis B). Then I asked my GP whether there's any treatment, and he said it can be  
209 treated. Then I went to see the doctor (specialist). (Participant 17, male, 70y)

210 The death of a friend or family members served as the motivator for three participants to  
211 seek clinical care.

212 I didn't pay attention to it when I first found out about it, because I didn't feel any  
213 problem, right? Then I had problems finding a job...had a lot of restrictions, and  
214 then... my family member... probably died from this virus. Then of course, there's an  
215 impact on myself, so I would pay special attention to this matter. (Participant 14,  
216 male, 43y)

217 What happened is that this girl friend of mine, her brother passed away with liver  
218 cancer because of hep B... And she told me 'you should go and see a  
219 gastroenterologist to help you monitor it', so that's why I came. (Participant 20,  
220 female, 50y)

221 Though some participants delayed engagement in clinical care, ten participants clearly  
222 indicated that they started regular clinical monitoring directly after being first diagnosed. A

223 common experience was that they were either provided with a clear message from either a  
224 doctor, blood donation staff, hepatitis B organisation, or family member to undertake  
225 regular blood tests, or were referred to a specialist directly after diagnosis.

226 *From the first (time) I was diagnosed, the doctor said you just keep an eye on your*  
227 *liver function, maybe every year, or maybe every two to three years at least.*  
228 *(Participant 6, female, 38y)*

229 *I was very little (when first diagnosed) ...In China, she (my mother) had me do regular*  
230 *blood tests. (Participant 26, female, 41y)*

231 *When my family doctor found out I had hepatitis B, he sent me to see the*  
232 *specialist...from that moment, until now, follow the treatment. And I keep checking*  
233 *the blood. (Participant 22, male, 71y)*

#### 234 Enablers to retention in clinical management

235 In this study, twenty-nine participants were regular patients of the specialist liver clinic with  
236 most engaging over many years. Three intersecting attitudes were highlighted that  
237 explained why individuals chose to engage in long-term clinical management for CHB. These  
238 included perceived seriousness of consequences of CHB, perceived benefits of attending  
239 clinical management, and perceived 'no barrier' to attending clinical management. These  
240 beliefs were shaped by individuals' knowledge, experiences, and general beliefs in life (Table  
241 2).

#### 242 ***Perceived seriousness of consequence of CHB***

243 While participants expressed various levels of knowledge and understanding of the  
244 aetiology, transmission and pathophysiology about CHB, almost all understood that CHB  
245 increased their risk of cirrhosis, liver cancer and death. The source of this message mostly  
246 came from doctors, family members, or 'Google'.

247 *If I don't look at this seriously, I will have liver cancer: that's most important thing*  
248 *that I have been told. (Participant 19, male, 34y)*

249 *My own understanding, maybe hepatitis B and then... fatty liver... then cirrhosis, and*  
250 *finally... eventually leading to death. (interview 10, male, 55y)*

251 **Perceived benefits of attending CHB clinical management**

252 A belief that regular clinical monitoring and/or treatment would reduce the risk of cirrhosis  
253 and liver cancer was a motivating factor supporting engagement with continued monitoring  
254 of their infection and also reduced the anxiety related to living with CHB.

255 *Why do I come back? Cos I don't want to get liver cancer (laugh) (Participant 13,*  
256 *female, 38y)*

257 *If you are actively engaging in treatment, you don't have to worry too much actually.*  
258 *I asked my doctor, and I also read some information...some of the data suggested the*  
259 *chance of getting cancer is high, higher than the average person, but ... it is not much*  
260 *higher (if you take medicine). (Participant 14, male, 43y)*

261 Knowledge of, and attention to indicators such as 'liver function', 'ALT' or 'viral load' were a  
262 source of engagement and information for many of the participants. For some participants,  
263 being clinically managed provided them with information about the health of their liver and  
264 whether liver disease was progressing- having testing results within or close to normal range  
265 provided them reassurance that things were under control.

266 *I have been seeing doctors at this hospital for several years. At the beginning...there*  
267 *was this problem of high ALT. Now the test (results) is getting better, the virus is*  
268 *almost undetectable, and the transaminase is back to normal. Now it's six-monthly*  
269 *check-ups. Well... for me, I feel that I can control this thing now, so I am not so*  
270 *worried. In the past... there was no hope that it might get better, such a situation...I*  
271 *was very anxious. (Participant 10, male, 55y)*

272 *I have already had 20 years of treatment, I carry on, I don't want to listen to anything*  
273 *(else) ... Because I found that I become better depends on the results, so I just ignore*  
274 *everything else. (Participant 16, male, 63y)*

275 Not all participants understood the benefits of long-term CHB monitoring from a biomedical  
276 perspective; what kept them attending regular clinical management was a general belief of  
277 the benefits of health check-ups, and trust in medical professionals.

278 *Well if you can have it checked regularly, it is definitely good. Of course, all those*  
279 *(blood) indicators have their scientific basis, that's why I think that it is better to*  
280 *check regularly, that's why I went to regular check-ups. (Participant 28, male, 48y)*

281 *And I honestly, had not much idea about what it involves. If the doctor tells you to*  
282 *come back, you just come back. (laugh) (Participant 13, female, 38y)*

283 For some participants, family obligations required them to take an active role in their health,  
284 and while not necessarily being specific to CHB, this also contributed to their retention in  
285 CHB clinical management.

286 *If I close my eyes, who look after my family? That's why I have to do it. (Participant*  
287 *16, male, 63y)*

288 *I feel like it is a responsibility towards my family to be healthy...keep relatively*  
289 *healthy overall in the long term... that seems to me is the biggest thing, and you have*  
290 *to be active, I've got young kids, and I take the kids to the park... (Participant 8, male,*  
291 *39y)*

292 A participant not on treatment expressed his doubts of the benefits of attending regular  
293 monitoring, however family support contributed to his adherence in clinical management.

294 *Every time I went in (to the doctor's office) was just chatting about the precautions,*  
295 *there is no actual action. Once I wanted to extend (to) yearly of the health*  
296 *examination, but my wife would urge, 'oh you better go', she kept saying that, and*  
297 *then I would also ... um, can't beat her (laugh). (Participant 28, male, 48y)*

### 298 ***Perceived 'no barrier' of attending CHB clinical management***

299 Participants were asked to identify whether there were barriers for them in attending  
300 regular appointments. Most reported no barriers; a participant who spoke limited English  
301 and had regular appointments with a doctor who spoke her language was highly  
302 appreciative of the clinical management she received and simply expressed "*no (barrier),*  
303 *nothing, not at all*". Two participants further specified no barrier in making time for  
304 attending appointments because they have "*flexible working hour*" and the clinic is "*off on*  
305 *the way*".

306 When people migrate to a new country, there can be competing priorities that impede  
307 healthcare access or delays in following up for chronic health problems. In our study, almost  
308 all participants who were first diagnosed in China or Malaysia were aware of the need to  
309 attend CHB clinical management prior to moving Australia, and promptly engaged in care  
310 after moving to Australia.

311 *I was hepatitis B carrier, and that's why I was sent a letter when I arrive in Australia*  
312 *when I got the permanent resident and they asked me to come and have like regular*  
313 *monitoring. (Participant 19, male, 34y)*

314 *They (doctors in Malaysia) just kept me going back to do blood tests, and then I*  
315 *moved back here about few year later. Usual GP thing, (I) told them I had been*  
316 *diagnosed with hepatitis B and...one doctor referred me to specialist (Participant 13,*  
317 *female, 38y)*

318 Some participants compared their experience of clinical management in Australia and  
319 overseas and identified specific enablers, particularly in relation to healthcare providers and  
320 the healthcare system in Australia. The most commonly mentioned factors appreciated by  
321 participants included the availability and use of an active reminder system, clear patient-  
322 doctor communication, the friendliness of medical staff, and subsidised healthcare services.

323 *It means easier... because the doctors keep an eye. And you know, (the clinic) send*  
324 *messages every six months so you'll come over to see your specialists. In China...no*  
325 *one is going to notify you. (Participant 15, female, 31y)*

326 *You know in Australia it's at public expense, it's paid by taxpayers, it's different from*  
327 *what's in China. If in China, it would cost (you) a lot of money. (Participant 23,*  
328 *female, 56y)*

329 *After I came here...Australia...I mean... the treatment for hepatitis... the strategy of*  
330 *treatment is good, the treatment process in hospital is also good, so I feel more*  
331 *secure. (Participant 10, male, 55y)*

332 *I found [doctor name] very pleasant...he has a long memory which impresses me that*  
333 *he remembers details by his patients that he heard a year ago, that's kind of shows*  
334 *that he cares or he actually listens. (Participant 13, female, 38y)*

## 335 **Discussion**

336 To achieve global and national hepatitis B elimination goals and reduce hepatitis B-related  
337 mortality, strategies to retain affected populations in regular clinical management are  
338 urgently required. However, little published evidence exists on how this retention can be  
339 effectively accomplished.

340 This paper identifies a series of enablers to linkage and retention in clinical management for  
341 CHB among ethnic-Chinese people in Australia. Three determinant beliefs, including  
342 perceived seriousness of consequences of CHB, perceived benefits of clinical management,  
343 and identification of barriers to attending clinical management, explain why these study  
344 participants attended for regular CHB clinical management. These beliefs were affected by  
345 an individual's knowledge, experiences, and other general beliefs as well as interactions  
346 occurring between individual characteristics and environmental factors.

347 Comprehensive support from the community, healthcare providers, and healthcare system  
348 are needed to support people living with CHB engage in regular clinical management.  
349 Enablers identified in this study that could be promoted include: a clear and unequivocal  
350 message that CHB increases risks of cirrhosis and liver cancer but effective and cheap  
351 treatment is available; the necessity and benefits of long-term clinical management; using  
352 clinical markers in patient-doctor communication to visualise disease status; timely referral;  
353 support from family, peer group and medical professionals; using hospital reminder  
354 systems; provision and use of interpreters and/or multilingual doctors; and subsidised  
355 healthcare services (Table 2).

356 The perceived seriousness of consequences of CHB, that is, CHB increases risks of cirrhosis  
357 and liver cancer, was among the major enablers identified to engagement in clinical care,  
358 highlighting the necessity of public health efforts to promote this information. Most  
359 participants in our study were over the age of 40 and had been diagnosed many years  
360 previously; for many, their diagnosis was prior to the availability of highly effective antiviral

361 therapy. Two potent oral antivirals, entecavir and tenofovir, have been recommended as  
362 first-line treatment options for CHB since 2006 and 2009, respectively<sup>21-24</sup>, and have been  
363 reimbursed by the national insurance scheme in Australia since this time<sup>25</sup>. In our study, the  
364 lack of effective treatment at the point of diagnosis was among the main reasons  
365 participants disengaging in CHB clinical management earlier in their illness; some re-  
366 engaged in CHB clinical management by finding out treatment being available, or getting a  
367 referral to a specialist. In contrast, successfully engaged participants shared similar  
368 experiences of receiving unequivocal messages that regular monitoring of their infection  
369 was necessary. There is an opportunity to engage those who are not aware of treatment or  
370 hold the view that “nothing can be done or needs to be done” in clinical management by  
371 promoting treatment availability and the necessity of long-term clinical monitoring.

372 In this study, healthcare providers were identified to play a critical role in supporting  
373 patients maintaining regular and sustained clinical management, with enablers including  
374 being a reliable source of health information, establishing clear communication, actively  
375 engaging with patients including providing information about CHB clinical markers and their  
376 role, empathy and professionalism. The use of key clinical indicators in CHB (e.g. ALT and  
377 HBV DNA) with patients was useful for several participants in supporting doctor-patient  
378 communication. The benefits of using these indicators provided patients with insight into a  
379 view of their largely asymptomatic disease, a better understanding of the role of clinical  
380 monitoring, an active involvement in their clinical management plan, and an intersection for  
381 the development of relationship between physician and patient.

382 As opposed to the findings from previous studies that reported barriers to healthcare access  
383 among CALD community, such as the fixed outpatient schedule times, complicated clinic  
384 setup, long waiting lists, or transportation barriers<sup>11, 12, 26</sup>, participants in this study reported  
385 tertiary care for CHB management as easy, free and constituting no barrier to retention in  
386 clinical care. This is likely related with the selection bias as the recruitment was conducted in  
387 a tertiary clinic with publicly funded healthcare services, however, this also suggested the  
388 healthcare system-based enablers. A few system-based enablers were highlighted, when  
389 participants compared their experiences of health services access in Australia and overseas,  
390 that make attending CHB clinical management easier, including a well-managed recall  
391 system, a supportive medical team, clear patient-doctor communication, and largely funded

392 healthcare services. The availability of interpreters and multilingual physicians, while not  
393 specifically highlighted in the interviews, was observed in the field to facilitate access to  
394 health services for participants with limited English-speaking skills. Recent years have seen  
395 support for decentralised care for CHB management<sup>7</sup>, and there is an opportunity to  
396 incorporate these enablers into community care models.

397 This study has several limitations. Firstly, participants were recruited from a single site  
398 based in a public hospital and located in an urban area and they had been successfully  
399 linked into specialist care. Their experiences may not reflect those of the broader Chinese  
400 community, which includes people who are not appropriately linked to specialist care,  
401 people with limited experience or confidence negotiating the Australian healthcare  
402 landscape and people with little or no access to healthcare services. Moreover, our sample  
403 could only provide insight into enablers rather than barriers to linkage to specialist care.  
404 However, these enablers are critical in design of interventions to support attending clinical  
405 management in people with CHB from Chinese community. Findings in this study may not  
406 be generalisable to other ethnic groups.

407 This study only included people speaking Mandarin and/or English and a significant  
408 proportion of Australia's Chinese community speak Cantonese as their main language<sup>27</sup>; as  
409 such the study findings might not reflect broader experience in the community and enablers  
410 that are unique to groups speaking other Chinese languages.

411 Previous studies suggest that different cultural beliefs and the use of alternative treatments  
412 such as Traditional Chinese Medicine is associated with people stopping CHB clinical  
413 management<sup>11</sup>. In our study, while some participants reported taking herbal medicine and  
414 expressing traditional health beliefs, no participant reported experiencing conflicts between  
415 cultural beliefs and western medicine clinical management plans. Thus, the findings of our  
416 study might not be sufficient to address barriers for people with dominant traditional  
417 Chinese health beliefs.

418 Lastly, using the health belief model to understand an individual's health behaviour is  
419 susceptible to the limitations of using just one theory, as well as the limitations of the health  
420 belief model per se. This model while having an individual-level focus may neglect factors  
421 beyond individual's motivation and beliefs, such as the modifying factors shaping their

422 beliefs, and particular cultural, social and community contexts. However, on the basis of the  
423 model, we further included factors of individual's knowledge, experience, general beliefs, as  
424 well as the interaction with external factors, based on themes generated from the data.

425 In conclusion, this study identified enablers supporting retention of people living with CHB  
426 in clinical management. Key enablers to linkage and retention in clinical management were  
427 provision of essential information including that CHB can lead to serious consequences, that  
428 effective and cheap treatment is available, and long-term clinical management is necessary  
429 and will reduce the risk of complications. This message needs to be delivered to newly  
430 diagnosed people as well as those people with CHB who were diagnosed before effective  
431 treatments were available. The use of clinical indicators by healthcare providers can help  
432 visualise the disease status and act as a tool for engagement between patient and clinician.  
433 Providing information to patients about the structure, funding, and organisation of the  
434 Australian healthcare system will support patient retention in CHB clinical management.  
435 This work supports the needs of actions from the community and healthcare providers, as  
436 well as development of public health programs, to engage people living with CHB in clinical  
437 management.

Author Manuscript

## References

1. Maucort-Boulch D, de Martel C, Franceschi S, Plummer M. Fraction and incidence of liver cancer attributable to hepatitis B and C viruses worldwide. *International Journal of Cancer*. 2018/06/15 2018;142(12):2471-2477. doi:10.1002/ijc.31280
2. Trépo C, Chan HLY, Lok A. Hepatitis B virus infection. *The Lancet*. 2014;384(9959):2053-2063. doi:10.1016/s0140-6736(14)60220-8
3. WHO. *Global Health Sector Strategy on Viral Hepatitis 2016-2021*. 2016.
4. European Association for the Study of the Liver. EASL 2017 Clinical Practice Guidelines on the management of hepatitis B virus infection. *Journal of Hepatology*. 2017;67:29.
5. Digestive Health Foundation, Gastroenterological Society of Australia. Australian and New Zealand Chronic Hepatitis B (CHB) Recommendations 2ND Edition 2009/10. <https://www.gesa.org.au/resources/clinical-guidelines-and-updates/chronic-hepatitis-b/>
6. MacLachlan J, Smith C, Towell V, Cowie B. *Viral Hepatitis Mapping Project: National Report 2018-19*. 2020. <https://ashm.org.au/programs/Viral-Hepatitis-Mapping-Project/>
7. Department of Health. *Third National Hepatitis B Strategy 2018-2022*. 2018.
8. MacLachlan JH, Cowie BC. Cultural and linguistic diversity of people living with chronic hepatitis B in 2011-2016: changing migration, shifting epidemiology. *Aust N Z J Public Health*. Oct 2018;42(5):441-443. doi:10.1111/1753-6405.12826
9. Cultural and Indigenous Research Centre Australia. *Consumer health information needs and preferences: perspectives of culturally and linguistically diverse and Aboriginal and Torres Strait Islander people*. 2017.
10. Vedio A, Liu EZH, Lee ACK, Salway S. Improving access to health care for chronic hepatitis B among migrant Chinese populations: A systematic mixed methods review of barriers and enablers. *Journal of Viral Hepatitis*. Jul 2017;24(7):526-540. doi:10.1111/jvh.12673
11. Lin W-S, Lee T-T, Yang Y-H, Mills ME. Environmental factors affecting self-management of chronic hepatitis B from the patients' perspective. *Journal of Clinical Nursing*. 2019/11/01 2019;28(21-22):4128-4138. doi:10.1111/jocn.14973

12. Fang DM, Stewart SL. Social-cultural, traditional beliefs, and health system barriers of hepatitis B screening among Hmong Americans: A case study. *Cancer*. 2018/04/01 2018;124(S7):1576-1582. doi:10.1002/cncr.31096
13. Wallace J, Pitts M, Liu C, et al. More than a virus: a qualitative study of the social implications of hepatitis B infection in China. *Int J Equity Health*. Aug 1 2017;16(1):137. doi:10.1186/s12939-017-0637-4
14. Na L, Na B. A revolutionary road: an analysis of persons living with hepatitis B in China. *J Health Commun*. 2013;18(1):71-91. doi:10.1080/10810730.2012.688449
15. Sievert K, O'Neill P, Koh Y, Lee JH, Dev A, Le S. Engaging new refugee in Australian communities at risk for chronic hepatitis B infection into care: A peer-educator intervention. *Health Soc Care Community*. Jul 10 2018;doi:10.1111/hsc.12602
16. Ortiz E, Scanlon B, Mullens A, Durham J. Effectiveness of Interventions for Hepatitis B and C: A Systematic Review of Vaccination, Screening, Health Promotion and Linkage to Care Within Higher Income Countries. *J Community Health*. Jul 22 2019;doi:10.1007/s10900-019-00699-6
17. Robotin MC, George J. Community-based hepatitis B screening: what works? *Hepatology international*. 2014;8(4):478-92. doi:<https://dx.doi.org/10.1007/s12072-014-9562-4>
18. Clarke V, Braun V, Terry G, Hayfield N. Thematic Analysis. In: Liamputtong P, ed. *Handbook of Research Methods in Health and Social Sciences*. 2019.
19. Nutbeam D, Harris E, Wise M. *Theory in a Nutshell: A Practical Guide to Health Promotion Theories*. 2010.
20. Glanz K, Rimer BK, Viswanath K. *Health Behavior : Theory, Research, and Practice*. John Wiley & Sons, Incorporated; 2015.
21. Members A-HA-PSC. Chronic hepatitis B: treatment alert. *Liver International*. 2006/12/01 2006;26(S2):47-58. doi:10.1111/j.1478-3231.2006.01374.x
22. Keeffe EB, Dieterich DT, Han SH, et al. A treatment algorithm for the management of chronic hepatitis B virus infection in the United States: an update. *Clin Gastroenterol Hepatol*. Aug 2006;4(8):936-62. doi:10.1016/j.cgh.2006.05.016
23. European Association For The Study Of The L. EASL Clinical Practice Guidelines: management of chronic hepatitis B. *J Hepatol*. Feb 2009;50(2):227-42. doi:10.1016/j.jhep.2008.10.001

24. Lok AS, McMahon BJ. Chronic hepatitis B: update 2009. *Hepatology*. Sep 2009;50(3):661-2. doi:10.1002/hep.23190
25. Department of Health. Pharmaceutical Benefits Scheme (PBS). 2020. <http://www.pbs.gov.au/pbs/home>
26. Leung AY, Bo A, Hsiao HY, Wang SS, Chi I. Health literacy issues in the care of Chinese American immigrants with diabetes: a qualitative study. *BMJ open*. Nov 18 2014;4(11):e005294. doi:10.1136/bmjopen-2014-005294
27. Australian Bureau of Statistics. 2016 Census: Multicultural. Updated 2018. <https://www.abs.gov.au/ausstats/abs@.nsf/lookup/Media%20Release3>

## Tables

Table 1. Characteristics of interview participants.

Characteristics	Number (%) (n=30)
<b>Female</b>	14 (47%)
<b>Age, years (median, IQR)</b>	49 (38-63)
<b>Birthplace</b>	
<b>Mainland China</b>	19 (63%)
<b>Malaysia</b>	5(17%)
<b>Taiwan</b>	2 (7%)
<b>Other or birthplace not provided during interview</b>	4 (14%)
<b>Main language of interview</b>	
<b>English</b>	14 (47%)
<b>Chinese</b>	16 (53%)
<b>Any family member(s) have hepatitis B</b>	
<b>Yes</b>	22 (73%)
<b>No or unsure or information not provided in interview</b>	8 (27%)
<b>Treatment status</b>	

<b>Not on treatment</b>	9 (30%)
<b>On treatment</b>	19 (63%)
<b>Information not provided during interview</b>	3 (7%)
IQR= interquartile range	

Author Manuscript

Table 2. Determinant beliefs for attending chronic hepatitis B (CHB) clinical management, supporting factors in aspects of individuals' knowledge, experiences, general beliefs, and applications.

<b>Determinant beliefs for attending CHB clinical management</b>	<b>Factors that contribute to this belief (knowledge/ experiences/ general beliefs)</b>	<b>Applications</b>
<b>Perceived seriousness of consequences of CHB:</b> <ul style="list-style-type: none"> <li>• Leading to cirrhosis</li> <li>• Increasing risks of liver cancer</li> <li>• Likelihood to get social rejections</li> </ul>	Knowledge of prognosis of CHB	Knowledge- sources of information: <ul style="list-style-type: none"> <li>• Healthcare providers</li> <li>• Peer group/ hepatitis B organisations</li> <li>• Family members</li> <li>• Internet/ social media and public health campaign</li> </ul>
	Having known someone had CHB-related morbidity or deaths	
	Having had CHB-related symptoms	
	Having experienced CHB-related rejections	
<b>Perceived benefits of attending CHB clinical management:</b> <ul style="list-style-type: none"> <li>• Monitoring CHB progression</li> <li>• Reducing risks of liver cancer (with treatment)</li> <li>• Reducing likelihood of transmission (with treatment)</li> <li>• Understanding/monitoring one's health status to reduce mental</li> </ul>	Knowledge of effective treatment being available	Enablers from healthcare providers that improves relevant experiences: <ul style="list-style-type: none"> <li>• Key information provided at diagnosis</li> <li>• Timely referral from primary care providers to specialists</li> <li>• Clear doctor-patient communication using biomedical indicators</li> <li>• Friendliness and professionalism</li> </ul>
	Knowledge of the necessity of clinical management	
	Knowledge of liver function and/or viral load being an indicator for CHB progression	
	Experiences of improved health (symptoms, mental burden, testing results) following attending clinical management	
	General belief in medical technology	

burden	General trusts in medical professionals	Enablers in community that supports action:
<p><b>Perceived 'no barrier' of attending CHB clinical management:</b></p> <ul style="list-style-type: none"> <li>• Accessible services with minimal costs</li> <li>• Availability of reminder messages</li> <li>• Availability of interpreters or multilingual doctors</li> </ul>	Experiences attending clinical care in Australia and overseas	<ul style="list-style-type: none"> <li>• Peer group support</li> <li>• Family support</li> </ul> <p>Factors in healthcare system that reduces barriers of action:</p> <ul style="list-style-type: none"> <li>• Subsidised healthcare services</li> <li>• Patient recall system</li> <li>• Availability of interpreters</li> </ul>