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1 Barriers and opportunities for hepatitis B testing and contact tracing in a UK Somali population: a
2 qualitative study

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1 **Abstract**

2 Background. Chronic hepatitis B virus (HBV) frequently causes liver disease, and early identification
3 can improve outcome. The burden of chronic HBV infection in many economically developed
4 nations lies in migrant populations. Targeted HBV testing of migrants, and contact tracing for those
5 diagnosed, are public health objectives, but uptake has been fragmentary. This qualitative study
6 aimed to investigate understanding of hepatitis B and response to testing and contact tracing
7 amongst people of Somali ethnicity living in Bristol, UK.

8 Methods. The views of 30 people of Somali ethnicity living in Bristol were explored through focus
9 groups and semi structured interviews. Transcripts of audio-recorded interviews and focus groups
10 were imported into NVivo10 and inductive thematic analysis undertaken.

11 Results. Most participants lacked awareness of hepatitis B, and often co-identified hepatitis B with
12 'jaundice'. There were frequent misconceptions regarding transmission, natural history and
13 diagnosis, with hepatitis B commonly viewed as a relatively trivial, short lived, symptomatic disease.
14 Hepatitis B was generally not stigmatised. Lack of understanding of the disease was cited as the
15 major barrier to targeted testing and contact tracing.

16 Conclusion. These findings suggest public health initiatives to promote hepatitis B testing and
17 contact tracing within migrant Somali populations should focus on improving hepatitis B
18 understanding, particularly its natural history and diagnosis, and avoid translation of 'hepatitis B'
19 into terms meaning 'jaundice' to address misperception of low susceptibility and low severity.

20 **Keywords:** hepatitis B; screening; contact; Africa; qualitative; migrant

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1 Introduction

2 Chronic hepatitis B virus (HBV) infection frequently causes cirrhosis and liver cancer. Early diagnosis
3 can improve outcome through hepatocellular carcinoma (HCC) surveillance and antiviral therapy.
4 HCC surveillance increases survival (1, 2), while antiviral therapy improves surrogate markers of
5 disease progression and is expected to demonstrate improved survival (3). In addition early
6 diagnosis can prevent onward transmission through vaccination of contacts (4).

7 In many developed nations, including the UK, the burden of chronic HBV infection lies within migrant
8 communities, and screening of migrants for HBV is recommended (5-9). The cost effectiveness
9 of HBV screening depends on adequate uptake of testing and engagement with monitoring,
10 treatment and vaccination, which have been poor in migrant communities (10-17). Engagement of
11 migrant populations with health services has been shown to be affected by a number of common
12 factors, including accessibility and language services, but qualitative studies have also identified
13 culture specific understanding of hepatitis B as an important determinant of engagement (18-34).

14 As only approximately 15-25% of people with chronic HBV infection develop liver cirrhosis or HCC,
15 many of those diagnosed derive limited health benefit from their diagnosis and can experience harm
16 through anxiety and time lost to consultations. In societies where the disease is stigmatised the
17 harms can be significant and may outweigh the benefits for some individuals. Significant stigma has
18 been described in West African migrants in USA (28-32), and indigenous Ghanaians (35), as well as a
19 number of Asian migrant populations (27, 34).

20 Thus to ensure cost effectiveness of HBV screening and to avoid harm a clear understanding of
21 cultural attitudes to hepatitis B in migrant populations is required. In this paper we report the
22 findings of a qualitative study that examined knowledge and perceptions of hepatitis B in a migrant
23 Somali population. We chose to study a single ethnic group in order to achieve greater depth of
24 enquiry into culture specific determinants of understanding of hepatitis B, including exploration of
25 the role of language in perpetuation of misconceptions. The aim was to provide information to

1 foster culturally appropriate implementation of HBV screening and contact tracing to maximise
2 engagement and minimise harm. We chose to study a Somali migrant population as, compared to
3 West African and Asian populations, studies exploring the East African cultural understanding of
4 Hepatitis B have been limited (27-34). Also, significant Somali migrant populations are present in a
5 number of nations where hepatitis B testing is recommended, including USA, Canada, Netherlands
6 and UK.

7 Approximately 97,000 people born in Somalia are living in the UK with large populations in London,
8 Liverpool and Bristol where this study was based (36, 37). The Bristol Somali population numbers
9 around 7,000 with a HBV prevalence of 2.9% (38) and was chosen for this study as the city hosts a
10 strong community health advocacy enterprise which was expected to optimise study engagement.

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1 **Methods**

2 Data was collected using qualitative research methods between February and July 2014. Adults of
3 Somali ethnicity living in Bristol UK, were recruited through informal community networks by Somali
4 community health advocates. Purposive sampling taking account of gender, age, levels of education,
5 duration living in the UK and employment status was used to select participants to capture variation
6 in views and experiences.

7 Recruits reporting that they had not previously been diagnosed with HBV infection were invited to
8 participate in one of four focus groups which were organised separately for women (focus groups 1
9 and 2) and men (focus groups 3 and 4) and each comprised 4 to 8 recruits. Focus groups 1 to 3 were
10 held in Somali with the assistance of an interpreter, focus group 4 was held in English. The focus
11 groups explored the participants understanding of hepatitis B, and used targeted screening and
12 contact tracing scenarios to understand barriers and triggers to engagement.

13 Recruits reporting that they had been previously diagnosed with hepatitis B infection were invited to
14 participate in one-to-one interviews which aimed to explore their experiences of hepatitis B
15 infection. Topic guides, informed by the Health Belief Model (39) were used to facilitate the focus
16 group discussions and semi-structured interviews so perceived susceptibility and severity of hepatitis
17 B, barriers and benefits, and cues to action as they related to hepatitis B testing could be explored.
18 Focus groups and interviews lasted approximately 1 hour, and were conducted in community
19 centres convenient for participants.

20 Focus groups and interviews were audio recorded, transcribed, anonymized, checked for accuracy
21 and then imported into the software package NVivo10. Data collection and analysis were conducted
22 in parallel and continued until data saturation in major themes was reached (40). Data-driven
23 inductive thematic analysis (41), was used to scrutinise the data in order to identify and analyse
24 patterns across the dataset using constant comparison techniques (42). Transcripts were examined
25 on a line-by-line basis and an initial coding frame developed by AC. A subset of transcripts was

1 independently analysed by JH to contribute to the generation and refinement of codes and thematic
2 categories to maximize rigor.

3 All participants received written and verbal information about the research and provided written
4 informed consent. Ethical approval for the study was obtained from the NHS National Research
5 Ethics Service Committee London - Camden & Islington 13/LO/11/80.

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1 **Results**

2 A total of 49 adults were approached of whom 30 participated. The mean age of participants was 50
3 years (range 32 to 71), 17 were women, 28 spoke Somali as their first language and all were Muslim.
4 Participants varied in relation to education, language ability and hepatitis B exposure (Table 1). The
5 analysis identified key themes which are illustrated below with the use of anonymised transcript
6 extracts (Tables 2 to 4). Additional relevant extracts are provided as supplementary material. In the
7 extracts ‘. . .’ indicates that words from the original verbatim quote have been omitted (repetition,
8 digressions or unclear speech). Participants are identified by a pseudonym (A to H), and a focus
9 group (number 1 to 4) or an interview (letter ‘i’).

10 **Awareness, understanding and stigma of hepatitis B**

11 Most participants were not familiar with the English language term ‘hepatitis B’ (Table 2). This
12 included some who spoke English and had a high level of formal education. A minority of
13 participants, particularly those who knew someone diagnosed with hepatitis B in Europe, had an
14 appreciation of its major characteristics but felt that the disease was not well understood in the
15 Somali community (Table 2 and supplementary data).

16 The few participants who were familiar with the term ‘hepatitis B’ often explained it within their
17 group using the English term ‘jaundice’ or the Somali terms ‘Joonis’, ‘Cagaarshow’ and ‘agaarhou’
18 meaning yellowing or greening of the skin and eyes. Some participants used the terms hepatitis B
19 and jaundice interchangeably, while others became confused about the use of the two terms (Table
20 2 and supplementary data).

21 When asked about the cause of hepatitis B (which had already become co-identified with jaundice
22 within the groups), a change in diet or excess fatty food was most commonly voiced (Table 2).

23 Drinking unclean water was also suggested, and three English speaking participants mentioned a
24 virus or bacteria (there is no word in Somali for virus, bacteria or germ). When asked about

1 transmission, the majority who responded said they didn't know how HBV was transmitted or how
2 to prevent transmission, while a few suggested it was transmitted by poor sanitation, sexual routes,
3 blood transfusion or sharing food (Table 2).

4 The focus group participants were unanimous that hepatitis B was not stigmatised in Somali culture,
5 and none of the four participants interviewed (who had been diagnosed with Hepatitis B) indicated
6 that they had felt stigmatised by their diagnosis. One interview participant suggested that though
7 jaundice was not traditionally stigmatised in Somalia, he felt that as people began to understand
8 more about it stigma was beginning to emerge (Table 2).

9 **Response to public health messages**

10 To explore targeted screening of migrants, examples of posters and letters (in English and Somali)
11 recommending hepatitis B testing of people born in high prevalence countries were discussed.

12 Participants were asked to consider how UK Somali's would respond to the health messages
13 provided. The general response was positive, with all groups indicating that Somali's would have a
14 desire and duty to look after their health and that of their family (Table 3).

15 There was consensus that the majority of UK Somali's would not engage with hepatitis B posters, but
16 that a letter directly sent to them would usually prompt them to seek further information and
17 testing, (Table 3 and supplementary data). Reasons given for not attending for testing included
18 misconceptions of the nature of hepatitis B. For example, the misconception that 'jaundice' (and by
19 association hepatitis B) was a relatively trivial disease without long term consequences was
20 consistent across all focus groups (supplementary data), and was cited as a deterrent to testing and
21 to engagement with the information provided.

22

23 Misconceptions regarding the transmission route and natural history of the disease were also cited
24 as deterrents, with participants saying that some people in their community would feel that they

1 couldn't have 'jaundice' (and thus hepatitis B) if they had a good diet, or had no symptoms (Table 3).
2 Finally, a number of participants said they believed that an unrelated visit to the doctor, some
3 general blood tests or other health screening would pick up hepatitis B, and that this would deter
4 testing.

5 In both the male focus groups participants expressed the view that Somali people would be
6 suspicious of a public health intervention targeting a single racial group, and would find this
7 stigmatising. An intervention targeted more widely was acceptable (Table 3).

8 Response to contact tracing was explored through the scenario of a newly diagnosed Somali who is
9 informed by his/her GP of the transmission routes, and advised that his/her partner, children and
10 other family members living in the same house should be tested and vaccinated. There was
11 consensus that the person with hepatitis B has a strong duty to disclose given that the disease is
12 transmissible, and that telling their contacts that they had hepatitis B (or jaundice) would be easy as
13 there is no stigma or embarrassment associated with the disease (Table 3). This expectation was
14 backed up in the one-to-one interviews where all participants asked (three of the four) said they had
15 disclosed to their family.

16 While it was considered easy to disclose the diagnosis, there was consensus that explaining the
17 transmission routes and the risk of cirrhosis or cancer would be difficult, as these would not concur
18 with expected attributes of 'jaundice' (Table 3). Again, this difficulty was confirmed by the
19 interviewees.

20 An additional theme that emerged from the female focus groups was concern that male partners
21 might not attend for testing and vaccination (supplementary data). Reasons given were that if the
22 man was healthy, he wouldn't feel he needed to go, or that he was likely to believe that his health
23 had already been checked, or that men in general are reluctant to go to the doctor. The idea that
24 men would not take the risk seriously was also expressed by one of the interview participants (Table
25 3).

1 In the male focus groups there was acknowledgement that women would be more concerned than
2 men, but the majority voice was that most male Somali contacts would attend for testing and
3 vaccination. When asked why some male contacts might not go, the only reason volunteered was
4 lack of understanding (supplementary data).

5 **Overcoming barriers to engagement**

6 When asked what would increase engagement with testing and contact tracing, 'information' was
7 suggested most frequently across all focus groups. Where the facilitator questioned whether
8 information alone would be sufficient to reverse misconceptions, it was felt that it would. For
9 example, regarding symptoms, there appeared to be no conceptual resistance to the possibility of an
10 asymptomatic disease, rather symptoms were expected for this particular disease ('jaundice').

11

12 The most effective media for delivery of information was discussed. To increase awareness of
13 hepatitis B, radio, television and group discussions were suggested as useful, with oral
14 communication generally regarded as more effective than written (Table 4). To attract people for
15 testing, the consensus was that letters addressed to individuals would have a big impact so long as
16 they were translated properly into Somali (Table 4), and that people could be supported to attend by
17 talking to a member of the Somali community who had experience of hepatitis B (supplementary
18 data). Other written information was also valued, particularly during the process of contact tracing
19 where a proposal to supply the index case with written information for the contact was welcomed
20 (supplementary data).

21 Regarding information content participants emphasised that sufficient information should be
22 presented so the person can understand the disease and overcome their misconceptions. The
23 information most commonly cited as important was that hepatitis B could result in a serious or fatal
24 outcome (Table 4). Participants were also concerned that information regarding targeted testing of

1 migrants should be explicit in the inclusion of migrants from a number of continents not just Africa in
2 order to avoid generation of stigma against Africans.

3 **Discussion**

4 This study explored understanding of hepatitis B and response to targeted screening and contact
5 tracing from the perspective of a UK migrant Somali population. To our knowledge this study is the
6 first to address these issues in a Somali population. Strengths of the study include the diverse
7 background and demographic of our participants, and the use of interpreters to explore the opinions
8 of non-english speaking participants. Limitations include the restricted geographic area for
9 recruitment.

10 We found no common cultural understanding of hepatitis B. Of interest, participants who initially
11 had no understanding of hepatitis B, came to co-identify hepatitis B with jaundice both through
12 explanations from other group members, and through translation of hepatitis B into words meaning
13 jaundice by interpreters. This progression occurred in all the focus groups, and is likely to be
14 reflected outside the research setting as translation of 'hepatitis B' into terms meaning jaundice is
15 common in medical interpretation and in currently available patient information leaflets in print and
16 on line (43, 44). As jaundice (and the Somali terms 'joonis', 'cagaarshow' and 'agaarhou'), indicates
17 having yellow skin or eyes, this co-identification is in direct conflict with the largely asymptomatic
18 nature of hepatitis B. Given migrant screening and testing of contacts aims to diagnose the infection
19 during its asymptomatic phase, co-identification with jaundice may be a barrier to testing.

20 A number of the other misconceptions we observed may be based on experience of other diseases
21 causing jaundice. For example, hepatitis A, which is a common cause of jaundice in Somalia, is
22 transmitted through unclean food and water, and is usually a relatively trivial disease from which
23 recovery is complete. Lack of awareness and diverse understandings of hepatitis B, including some
24 of the concepts reported here, have been described in previous studies of migrant populations (27,

1 45), but the key role of translation of 'hepatitis B' into words meaning 'jaundice' in generation of
2 misconceptions has not previously been suggested.

3 The Health Belief Model (39) components of perceived susceptibility and severity, perceived
4 benefits, barriers, and cues to action, have been used to explain why individuals' decide, or not, to
5 attend hepatitis B screening across diverse ethnic groups, (46) (47). We found that the Bristol
6 Somali population voiced factors cognisant with perceived susceptibility and severity as major
7 influences on decisions regarding testing. Thus the perceived non-susceptibility associated with lack
8 of symptoms, a healthy lifestyle and previous health checks; and the perceived non-severity of
9 'jaundice' were all cited as deterrents to testing in our study. In terms of perceived benefit, the
10 ability to protect their family through vaccination was voiced as highly valued. Structural and
11 cultural barriers to testing were not prominent, with the overriding opinion being that if
12 misperceptions regarding susceptibility and severity could be overcome, then testing would be
13 sought.

14 Our findings suggest that public health initiatives to promote hepatitis B testing in Somali migrant
15 populations should prioritise provision of clear information about the natural history of hepatitis B
16 to address misperception of low susceptibility and low severity, and should be cognisant of the role
17 of language in creation and perpetuation of misconceptions. Specifically, patient information
18 provided for Somalis should avoid translation of the term 'hepatitis B' into terms meaning jaundice,
19 should acknowledge but refute the erroneous co-identification of hepatitis B with jaundice, and
20 should emphasise the following points: 1) hepatitis B is usually asymptomatic; 2) hepatitis B can
21 affect you whatever your diet and lifestyle; 3) hepatitis B can cause severe illness; 4) standard health
22 checks and blood tests will not pick up hepatitis B. Regarding the delivery of information, the
23 preference indicated in our focus groups for oral and community based methods is in keeping with
24 the strong oral tradition within Somali culture, and suggests that radio, TV, community discussion
25 groups and opportunistic conversation with health professionals would be preferred methods.

1 Community health education has been successful in other public health initiatives in Somali
2 communities in the UK (48).

3

4 Our observations highlight that clear written information may be beneficial for people newly
5 diagnosed with hepatitis B, to help them explain to their contacts the rationale behind testing and
6 vaccination. Studies of hepatitis B contact tracing generally show poor uptake (14-17), indicating
7 room for significant public health benefit.

8 Unlike the qualitative research observations in West African populations where stigma towards
9 hepatitis B was a barrier to screening, and a cause of non-disclosure (28, 31), our findings suggest
10 that hepatitis B is not a stigmatised disease in the Somali community in Bristol, and stigma is not a
11 factor influencing testing or disclosure. We found some concern that hepatitis B may become
12 stigmatised as knowledge increases, and, as stigma has been negatively associated with testing in
13 other migrant communities (25, 26, 45), care should be taken to avoid undue emphasis of potentially
14 stigmatising aspects of the disease. Of more concern to our participants was that targeted testing of
15 migrants could stigmatise the targeted communities. Recent prevalence data suggests that
16 narrowing the target migrant population for screening by country of birth may be justified on cost
17 effectiveness grounds (38) increasing the potential for stigmatisation.

18 In conclusion, this study suggests that migrant Somalis in a large UK city feel a duty to look after their
19 health and that of their family, but have low awareness and understanding of hepatitis B, tend to
20 discuss hepatitis B using terms meaning 'jaundice', and harbour a number of disease
21 misconceptions. The lack of awareness and misconceptions represent likely barriers to engagement
22 with targeted screening and contact tracing which could be addressed through provision of culturally
23 appropriate information. The likely role of translation in generating misconceptions should prompt
24 a wider assessment of the knock on effects of the specific terms used in medical interpretation.

1

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8 the decision to submit for publication.

9 **Conflict of interest**

10 The authors report that apart from the study funding (documented in the acknowledgements), both
11 AC, PC and JH have no conflicts of interest to declare.

12

13 **Key points**

- 14 • This study suggests that lack of awareness and misconceptions of hepatitis B are major
15 barriers to testing in migrant Somalian populations.
- 16 • Perceived non-susceptibility and non-severity emerge as important disincentives to testing.
- 17 • Public health initiatives to raise awareness and knowledge should be careful to avoid
18 increasing misconceptions and introducing stigma.
- 19 • Particular attention should be paid to language in order to avoid co-identification of
20 hepatitis B with jaundice.
- 21 • The current lack of stigma and strong cultural duty of care for the family facilitates contact
22 tracing in this population.

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1 **References**

- 2 1. Zhang BH, Yang BH, Tang ZY. Randomized controlled trial of screening for hepatocellular
3 carcinoma. *Journal of cancer research and clinical oncology*. 2004;130(7):417-22.
- 4 2. Zhou XD, Tang ZY, Yang BH, Zhang BH. Hepatocellular Carcinoma: The Role of Screening.
5 *Asian Pacific journal of cancer prevention : APJCP*. 2000;1(2):121-6.
- 6 3. Liaw YF. Impact of therapy on the long-term outcome of chronic hepatitis B. *Clinics in liver*
7 *disease*. 2013;17(3):413-23.
- 8 4. Pazdiora P, Bohmova Z, Kubatova A, Menclova I, Moravkova I, Pruchova J, et al. Screening
9 family and sexual contacts of HBsAg+ persons in the Pilsen region. *Epidemiol Mikrobiol*
10 *Imunol*.61(3):51-7.
- 11 5. Ahmed F, Foster GR. Global hepatitis, migration and its impact on Western healthcare.
12 *Gut*.59(8):1009-11.
- 13 6. Recommendations for Identification and Public Health Management of Persons with Chronic
14 Hepatitis B Virus Infection. Coordinating Center for Health Information and Service, Centers for
15 Disease Control and Prevention (CDC), U.S. Department of Health and Human Services, Atlanta, GA
16 30333: Centre for Disease Control and Prevention, 2008 19/09/2008. Report No.: 57 (No. RR-8)
- 17 7. National Hepatitis B Virus (HBV) Testing Policy Expert Reference Committee a, (BBVSS)
18 jwpotBBVaSTISc, (MACBBVS). atMACoBBVaSTI. 2012 National Hepatitis B Testing Policy v1.1.
19 Australia2012.
- 20 8. NICE. Hepatitis B and C: ways to promote and offer testing to people at increased risk of
21 infection. NICE public health guidance 43 (2012).

- 1 9. Shah HA, Heathcote J, Feld JJ. A Canadian screening program for hepatitis C: is now the
2 time? CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne.
3 2013;185(15):1325-8.
- 4 10. Rein DB, Lesesne SB, Smith BD, Weinbaum CM. Models of community-based hepatitis B
5 surface antigen screening programs in the U.S. and their estimated outcomes and costs. Public
6 Health Rep.126(4):560-7.
- 7 11. Pollack H, Wang S, Wyatt L, Peng CH, Wan K, Trinh-Shevrin C, et al. A comprehensive
8 screening and treatment model for reducing disparities in hepatitis B. Health Aff
9 (Millwood).30(10):1974-83.
- 10 12. Hu DJ, Xing J, Tohme RA, Liao Y, Pollack H, Ward JW, et al. Hepatitis B testing and access to
11 care among racial and ethnic minorities in selected communities across the United States, 2009-
12 2010. Hepatology. 2013;58(3):856-62.
- 13 13. Williams S, Vally H, Fielding J, Cowie B. Hepatitis B prevention in Victoria, Australia: the
14 potential to protect. Euro Surveill. 2011;16(22).
- 15 14. Richardson G, Evans MR, Westmoreland D. Hepatitis B immunisation of household contacts:
16 retrospective study of vaccine coverage. Journal of epidemiology and community health.
17 2001;55(12):934-5.
- 18 15. Mascarenhas L, Mak DB. An audit of chronic hepatitis B contact tracing in metropolitan
19 Western Australia. Australian family physician. 2014;43(3):137-41.
- 20 16. Miles L, Roberts R, Casey D, Roberts C, Williams S. Hepatitis B: how many patients are
21 counselled on transmission prevention and how many contacts are offered vaccination? Commun
22 Dis Public Health. 2002;5(2):165-6.

- 1 17. Weinberg MS, Gunn RA, Mast EE, Gresham L, Ginsberg M. Preventing transmission of
2 hepatitis B virus from people with chronic infection. *American journal of preventive medicine*.
3 2001;20(4):272-6.
- 4 18. Chang ET, Nguyen BH, So SK. Attitudes toward hepatitis B and liver cancer prevention among
5 Chinese Americans in the San Francisco Bay Area, California. *Asian Pacific journal of cancer*
6 *prevention : APJCP*. 2008;9(4):605-13.
- 7 19. Chen H, Tu SP, Teh CZ, Yip MP, Choe JH, Hislop TG, et al. Lay beliefs about hepatitis among
8 North American Chinese: implications for hepatitis prevention. *J Community Health*. 2006;31(2):94-
9 112.
- 10 20. Choe JH, Chan N, Do HH, Woodall E, Lim E, Taylor VM. Hepatitis B and liver cancer beliefs
11 among Korean immigrants in Western Washington. *Cancer*. 2005;104(12 Suppl):2955-8.
- 12 21. Taylor VM, Yasui Y, Burke N, Nguyen T, Chen A, Acorda E, et al. Hepatitis B testing among
13 Vietnamese American men. *Cancer detection and prevention*. 2004;28(3):170-7.
- 14 22. Tran TT. Understanding cultural barriers in hepatitis B virus infection. *Cleve Clin J Med*.
15 2009;76 Suppl 3:S10-3.
- 16 23. Burke NJ, Do HH, Talbot J, Sos C, Svy D, Taylor VM. Chumnguh thleum: understanding liver
17 illness and hepatitis B among Cambodian immigrants. *J Community Health*. 2011;36(1):27-34.
- 18 24. Burke NJ, Jackson JC, Thai HC, Stackhouse F, Nguyen T, Chen A, et al. 'Honoring tradition,
19 accepting new ways': development of a hepatitis B control intervention for Vietnamese immigrants.
20 *Ethnicity & health*. 2004;9(2):153-69.
- 21 25. van der Veen YJ, de Zwart O, Voeten HA, Mackenbach JP, Richardus JH. Hepatitis B screening
22 in the Turkish-Dutch population in Rotterdam, the Netherlands; qualitative assessment of socio-
23 cultural determinants. *BMC Public Health*. 2009;9:328.

- 1 26. van der Veen YJ, Voeten HA, de Zwart O, Richardus JH. Awareness, knowledge and self-
2 reported test rates regarding Hepatitis B in Turkish-Dutch: a survey. *BMC Public Health*. 2010;10:512.
- 3 27. Jones LA, A. Porcellato, L. Bates, G. McCoy, E. Beynon, C. McVeigh, J. Bellis, M. A systematic
4 review of qualitative research on the views, perspectives and experiences of hepatitis B and C testing
5 among practitioners and people at greatest risk of infection. Centre for Public Health, Research
6 Directorate, Faculty of Health and Applied Social Sciences, Liverpool John Moores University, 2012.
- 7 28. Blanas DA, Nichols K, Bekele M, Shankar H, Bekele S, Jandorf L, et al. Adapting the Andersen
8 Model to a Francophone West African Immigrant Population: Hepatitis B Screening and Linkage to
9 Care in New York City. *J Community Health*. 2014.
- 10 29. Jorgensen CM, Carnes CA. Lessons learned from exploratory research about viral hepatitis.
11 *Health promotion practice*. 2013;14(3):364-9.
- 12 30. Shah SA, Chen K, Marneni S, Benchekroune G, Ariganjoye R, Purswani M, et al. Hepatitis B
13 Awareness and Knowledge in Hepatitis B Surface Antigen-Positive Parturient Immigrant Women
14 from West Africa in the Bronx, New York. *J Immigr Minor Health*. 2013.
- 15 31. Sriphanlop P, Jandorf L, Kairouz C, Thelemaque L, Shankar H, Perumalswami P. Factors
16 related to hepatitis B screening among Africans in New York City. *American journal of health
17 behavior*. 2014;38(5):745-54.
- 18 32. Wiecha JM. Differences in knowledge of hepatitis B among Vietnamese, African-American,
19 Hispanic, and white adolescents in Worcester, Massachusetts. *Pediatrics*. 1999;104(5 Pt 2):1212-6.
- 20 33. Owiti JA, Greenhalgh T, Sweeney L, Foster GR, Bhui KS. Illness perceptions and explanatory
21 models of viral hepatitis B & C among immigrants and refugees: a narrative systematic review. *BMC
22 Public Health*. 2015;15:151.
- 23 34. Sweeney L, Owiti JA, Beharry A, Bhui K, Gomes J, Foster GR, et al. Informing the design of a
24 national screening and treatment programme for chronic viral hepatitis in primary care: qualitative

- 1 study of at-risk immigrant communities and healthcare professionals. BMC health services research.
2 2015;15:97.
- 3 35. Mkwandawire P, Richmond C, Dixon J, Luginaah IN, Tobias J. Hepatitis B in Ghana's upper west
4 region: a hidden epidemic in need of national policy attention. Health & place. 2013;23:89-96.
- 5 36. Office for National Statistics [Internet]. UK statistics authority. 2013 [cited 9th September
6 2014]. Available from: <http://www.statistics.gov.uk/>.
- 7 37. Aweis D, Brabin BJ, Beeching NJ, Bunn JE, Cooper C, Gardner K, et al. Hepatitis B prevalence
8 and risk factors for HBsAg carriage amongst Somali households in Liverpool. Commun Dis Public
9 Health. 2001;4(4):247-52.
- 10 38. Cochrane A, Evlampidou I, Irish C, Ingles S, Hickman M. Hepatitis B infection prevalence by
11 country of birth in migrant populations in a large UK city. J Clin Virol. 2015 68:79-82.
- 12 39. Janz NK, Becker MH. The Health Belief Model: a decade later. Health education quarterly.
13 1984;11(1):1-47.
- 14 40. Sandelowski M. Sample size in qualitative research. Research in Nursing & Health. 1995;18.
- 15 41. Braun VC, V. Using thematic analysis in psychology. Qualitative research in psychology.
16 2006;3:77-101.
- 17 42. Glaser BS, AL. The Discovery of Grounded Theory: Strategies for Qualitative Research.
18 Chicago: Aldine Publishing Company; 1967.
- 19 43. Pregnant? Get tested for Hepatitis B - Somali. In: Health MDo, editor. Minnesota
20 Department of Health: Minnesota Department of Health.
- 21 44. Viral Hepatitis - Somali. In: Medline Plus: A service of the U.S. National Library of Medicine
22 NIOH, USA.

- 1 45. Li D, Tang T, Patterson M, Ho M, Heathcote J, Shah H. The impact of hepatitis B knowledge
2 and stigma on screening in Canadian Chinese persons. *Can J Gastroenterol*.26(9):597-602.
- 3 46. Ma GX, Fang CY, Shive SE, Toubbeh J, Tan Y, Siu P. Risk perceptions and barriers to Hepatitis
4 B screening and vaccination among Vietnamese immigrants. *J Immigr Minor Health*. 2007;9(3):213-
5 20.
- 6 47. van der Veen YJ, van Empelen P, de Zwart O, Visser H, Mackenbach JP, Richardus JH. Cultural
7 tailoring to promote hepatitis B screening in Turkish Dutch: a randomized control study. *Health*
8 *promotion international*. 2013.
- 9 48. Hearst MO, Kehm R, Sherman S, Lechner KE. Increasing fruit and vegetable consumption and
10 offerings to Somali children: the FAV-S pilot study. *Journal of primary care & community health*.
11 2014;5(2):139-43.

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Participants characteristics		Focus group participants	Interview participants
Gender	Male	14	3
	Female	12	1
Age Category (years)	25-34	3	0
	35-44	7	1
	45-54	6	0
	55-64	5	2
	65-74	3	1
	unknown	2	0
Duration of residence in UK	More than 5 years	16	4
	5 years or less	4	0
	Not recorded	6	0
Marital status	Married	17	2
	Single	5	2
	Divorced	1	0
	Not Recorded	3	0
Current employment status	Employed	6	1
	Unemployed	19	3
	Not recorded	1	0
Highest level of formal education	No formal education	3	2
	Left school before completing secondary level	5	0

	Completed secondary education or vocational training	7	0
	Completed university or college	9	2
	Not recorded	2	0
English language ability	No Verbal or written understanding	4	1
	Some verbal or written understanding	8	3
	Good verbal and written understanding	14	0
Ever tested for hepatitis B	Yes	8	4
	No	12	0
	Not recorded	6	0
Ever diagnosed with hepatitis B infection	Yes	1	4
Knows anyone who has been diagnosed with hepatitis B infection.	Yes	4	1
	No	15	3
	Not recorded	7	0

1 Table 1. Demographics, educational background and hepatitis B testing history of participants.

2

Theme	Illustrative quote
Understanding of hepatitis B and co-identification or confusion with jaundice	<p>Facilitator: "So first of all, I just wonder whether any of you have any ideas about hepatitis B, what it is, what it causes?"</p> <p>Mrs B2: "We don't know."</p> <p>Facilitator: "And you?"</p> <p>Mrs ?2: "Me too."</p> <p>Mrs F2: "Is it not like asthma, or something like that, linked up with that?"</p> <p>Mrs H2: "I think of the liver... more than asthma."</p> <p>Mrs?2: "Maybe fat or something "</p> <p>Mrs D2: "I think it causes the kid's headache and temperature."</p> <p>Mrs B2: "We used to have it in Somalia, it is jaundice, it affects the liver"</p> <p>....</p> <p>Mrs E2: "we had a family history of hepatitis B, some people say jaundice, some people say hepatitis B"</p> <p>Mr F3 "This [hepatitis B] is a disease that people know very little about, not so common as other like TB." (Man with experience of hepatitis B).</p> <p>Facilitator: "Ok, do you know or do you think there is any treatment for hepatitis B, have you heard of any treatment?"</p> <p>Mrs ?2 "We are getting confused between jaundice and hepatitis B."</p>
Cause and transmission of hepatitis B or 'jaundice'	<p>Mr Di: "The cause is malnutrition, constipation, and when someone is malnourished and then all of a sudden starts taking meat or fatty things, it is fatal, as long as you don't have the constipation and are healthy in that way, you don't catch it."</p>

Facilitator: “And do you know any way that hepatitis B can be transmitted, from one person to another? You have mentioned about food in the refugee camps.”

Mr A4: “I don’t know, I don’t think it is transmissible, I don’t know.”

Mr ?4 “It is sexually transmitted isn’t it?”

Mr E4: “If you get blood, blood transfusion.”

Mr A4: “And by food as well?”

Facilitator: “..do you know of any ways that you can stop yourself from getting hepatitis B?”

Mrs B1: “No.”

Mrs C1: “No idea.”

Mrs D1: “No”.

Diagnosis of hepatitis B	Mr Ai: “when we arrived at this country we had all health screening, and I think they could have picked up something if there was hepatitis B”.
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1 Table 2. Quotes illustrating awareness and understanding of hepatitis B and its diagnosis.

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Theme	Illustrative quote
Response to targeted hepatitis B screening	<p>Facilitator: "...how likely do you think it is, that she will really go to her GP and ask for a test?" [after seeing a poster]</p> <p>Mrs A1: "Yes, she will go and have a test"</p> <p>Mrs C1: "If she is completely well she wont go, she will ignore this piece of paper"</p> <p>Mrs B1: "if she knows something about hepatitis B she might go, but for someone like me, I wouldn't understand what it is about, so I just, I wouldn't even look at it, because I don't understand."</p> <p>Facilitator: "testing is not being promoted for everybody, ... it is being promoted for people born in Eastern Europe, Asia, Africa, South America, so do you think that would be wide enough [to avoid suspicion]?"</p> <p>Mr A4: "If they understand ...it is not just Somali's it is the rest of the world it is a lot of countries, a lot of people, that they accept, it's just they must understand, I mean [interrupted] they are not guinea pig" [laughter]</p>
Response to contact tracing	<p>Facilitator: "What do you think she will be thinking after this discussion with her GP?" [regarding contact tracing]</p> <p>Mrs C1: "If the doctor told her she can pass it on to other people then she must tell them"</p> <p>Mrs D1: "I agree"</p> <p>Mrs A1: "If she has been told this is dangerous to the family then she has to tell them."</p> <p>Facilitator: "Do any of you think that Amina's husband might blame her for catching it, or be angry with her?"</p> <p>Participants: [laughter]</p> <p>Mrs D2: "He will tell her like, 'you will be fine, don't worry'"</p>

Mrs ?2: “no no, not embarrassing, he wouldn’t be embarrassed”

Mrs?2: “he wouldn’t blame her; he would say ‘this is our destiny”

Mrs F2: “He will be worrying but he wouldn’t say ‘it is your fault”

Mrs C1: “It is easy to say ‘I have hepatitis B’ because it is just jaundice, but to say it is transmitted by this way, or sexually, this is harder, it is not what is expected”.

Facilitator: “....Why do you think people would not [attend for testing].....too busy?”

Mr F3: “I will tell why, lack of understanding and education, they don’t know how risky and how fatal this disease is. It is now only very few people who have known the fatality of this disease and many people will say, ‘oh [inaudible] why bother’, but only because they don’t know the risk of the disease.”

- 1 Table 3. Quotes illustrating response to targeted hepatitis B screening and contact tracing.

<i>Theme</i>	<i>Illustrative quote</i>
Overcoming barriers to testing and contact tracing	<p>Facilitator: "So do you think it would be possible to have a condition that was damaging your liver and you would still feel completely well?"</p> <p>Mrs E2: "Yes, because sometimes you have a serious problem and you don't know."</p> <hr/> <p>Facilitator: "Would there be anything that would help her to go? That makes it easy for her to go?" [referring to woman receiving advice to attend for a hepatitis B test]</p> <p>Mrs C1 or A1: "What can make her go maybe her family, if they're worried about, they may encourage her or maybe somebody who has an experience about hepatitis B, You know, maybe friends? Somebody who knows about this or had hepatitis themselves may encourage her."</p> <p>Facilitator: "And is there anything else you think we should put in the letter or something we should take out of the letter to make it more likely to get Amina [fictional character from scenario] to go to her GP?"</p> <p>Mrs D1: "If she understands what hepatitis B is, then she will definitely go, so the letter must be clear."</p> <p>Mrs A1: "The language that you write the letter in might make a difference, for example she might not be able to read English but she might be able to read Somali."</p>

Facilitator: "So what exactly should the letter say?"

Mr F3: "I think it would be emphasised more what is just mentioned here, er, ... more about the process, saying that this hepatitis B worsening to be a killer or fatal at the end, so people telling him how it develops even if you feel well, how it comes to an irreversible state or fatal, so if a lot of thought or literature is given to that then I think people will understand."

1 Table 4. Quotes illustrating overcoming barriers to engagement.

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