UK NATIONAL SCREENING COMMITTEE

Screening for Hepatitis B and Hepatitis C among ethnic minorities born outside the UK Policy Position Statement

10 March 2011

Aim

1. To agree the UK National Screening Committee's (UK NSC) formal policy position on screening for hepatitis B and hepatitis C among ethnic minorities born outside the UK.

Background

2. In October 2009, Sir Liam Donaldson (the former Chief Medical Officer for England) wrote to the Chair of the UK National Screening Committee (UK NSC) asking if the UK NSC would consider the Advisory Group on Hepatitis (AGH) Report: Case finding for hepatitis B and C virus infections in minority ethnic populations in the UK against the UK NSC's criteria for appraising the viability, effectiveness and appropriateness of a screening programme. In November 2009 the UK NSC agreed to undertake this request.

3. Dr Martin Allaby from Solutions for Public Health reviewed screening for hepatitis B virus and hepatitis C virus amongst people who were born in countries with high or intermediate prevalence of hepatitis B virus infection, as defined by the World Health Organisation (WHO) against the UK NSC's criteria for appraising the viability, effectiveness and appropriateness of a screening programme in April 2010.

4. The screening review concluded that it is not yet clear whether there is an effective means of identifying and issuing invitations to all individuals in the target population.

5. Many authorities state that, without therapy, between 20-30% of patients with chronic hepatitis B virus infection will die of complications such as cirrhosis or hepatocellular carcinoma. However, the review did not find any evidence from which the long-term (> 10 years) natural history of chronic hepatitis B virus infection among non-western individuals can be reliably inferred. The true figure may be more or less than 20-30%.

6. The review stated that the cost-effectiveness of the proposed screening programme needs to be assessed, using assumptions that are up to date, realistic and relevant in the UK context. Among the many other key variables included in other published studies, this needs to reflect:

- evidence-based estimates of the costs of identifying and inviting individual members of the target population (assuming this proves to be possible)

- the evolving proportion of hepatitis B virus positive individuals who are candidates for antiviral drugs (20% initially, rising to 50% by 20 years after screening)
- the likely beneficial effect of antiviral therapy on health-related quality of life in chronic hepatitis C virus
- an assessment of the proportion of migrants to the UK (particularly new migrants) that would be eligible for screening +/- treatment (thereby incurring costs to the NHS) but who would leave the country within a few years (so that their avoidance of serious liver disease does not contribute to NHS cost-savings)
- the reduction in cost-effectiveness if the eligibility criteria were to broaden from people who were born in countries with a high or intermediate prevalence of hepatitis B virus infection to those who originate in those countries, but were not born there.

Consultation

7. At the UK NSC meeting on 16th June 2010 members agreed that the review should be placed on the UK NSC website for consultation for three months. The consultation commenced on 3rd August 2010 and closed on 2nd November 2010. Attached at Annex A is a copy of the consultation replies.

Research

8. At the meeting in June, members agreed that following the consultation the research questions which need to be addressed should be submitted to the National Institute for Health Research (NIHR). A copy of the research questions are attached at Annex B. Members also agreed that Dr Mackie should write to the NIHR on behalf of the UK NSC supporting Professor Graham Foster's chronic viral hepatitis in ethnic minorities - strategies to prevent the predicted increase in mortality application for an applied research grant.

Recommendation

9. The UK NSC is asked to agree the policy position on screening for hepatitis B and hepatitis C among ethnic minorities born outside the UK as follows:-

A national screening programme for hepatitis B and hepatitis C among ethnic minorities born outside the UK is not recommended.

10. The UK NSC is asked to agree that the policy should be reviewed in three years time unless there is significant new peer reviewed evidence in the meantime.

Annex A

Consultation Replies

Royal College of General Practitioners

UK National Screening Committee (UK NSC) consultation on Screening for Hepatitis B and Hepatitis C among ethnic minorities born outside the UK

1. I write with regard to the UK NSC consultation on Screening for Hepatitis B and Hepatitis C.

2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. Founded in 1952, it has over 42,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline. We are an independent professional body with enormous expertise in patient–centred generalist clinical care. Through our General Practice Foundation, established by the RCGP in 2009, we maintain close links with other professionals working in General Practice, such as practice managers, nurses and physician assistants.

3. The College welcomes the opportunity to respond to this consultation. Broadly we find the expert review document to be well written and of good quality, and note that it appears to demonstrate fulfilment of Wilson's criteria for screening. Given that migration has changed the map of Hepatitis B and C in the UK and Europe, it seems appropriate that screening should be applied to this target group.

4. This is supported by the conclusions of a recent international conference[1] held in Brussels, which acknowledged 'that, while some member states have significant levels of infection in the general population, in others – including seven that do not have universal vaccination programmes: Denmark, Finland, Iceland, Netherlands, Norway, Sweden and the United Kingdom – HBV and BCV cases are for the most part confined to specific, high-risk groups. It is appropriate, therefore, that prevention activities should be targeted accordingly.'[2]

5. We were however surprised to be commenting on a document which does not address the key implementation challenges in the programme. There will need to be careful consideration of how to identify and encourage this population to take up the screening options, and consideration of the resource implications for the NHS.

6. Currently there is no trial evidence for a screening programme as proposed and it would be unwise to go down this road without evidence that it will work, as it will

[1] Summit conference: hepatitis B and hepatitis C, Brussels, 14-15 October 2010, http://www.hepsummit2010.org/.
[2] Health Protection Agency. Health Protection Report **Volume** 4 **No** 43; 29 October 2010 - http://www.hpa.org.uk/hpr/archives/2010/news4310.htm#tryp

have to be applied nationally, given that minority ethnic groups are dispersed in all wards though with clustering in metropolitan areas. We suggest a trial screening programme before national implementation, which may also allow some issues around stakeholder engagement and resource implications to be refined.

7. We recognise the problems identified in the document, particularly around identification of ethnic minorities applicable for screening. Recording of ethnicity data in primary care does not have a minimum required dataset. As discussed in the recent King's Fund report *Tackling Inequalities in General Practice*[3], QOF could have a valuable role in encouraging the collection of better data and thus enabling successful screening, if the evidence exists for the value of a minimum dataset.

8. With regards to paragraph 1 of the draft report, which quotes a recent report from the Department of Health's Advisory Group on Hepatitis, we would argue that contact tracing should be extended to sexual contacts of those found to be carriers during the screening or known to be carriers, as well as to anybody who might have been sharing syringes/needles with the carrier.

9. On the latter point, access to needle exchange programmes should be encouraged among those found to be Hepatitis C carriers and injecting drugs – and arguably for all who inject drugs.

10. It is also arguable that Hepatitis B and C status (as well as HIV status) should form part of immigration screening.

11. The paper does not discuss how the proposal that 'contacts who are negative for evidence of HBV infection or immunity should be offered HBV vaccine' (paragraph 1) would be supported. If this is to be through GPs, there will be a need for a DES (directed enhanced services) agreement.

12. We gratefully acknowledge the contributions of college experts in formulating this response.

13. Given the preliminary nature of the consultation, without focus on specific recommendations, we would prefer that this response not be posted on the NSC website; we are happy however to be approached for more formal views in due course.

Yours sincerely

Professor Amanda Howe
Honorary Secretary of Council

[3] Hutt P, Gilmour S. Tackling Inequalities in General Practice (The King's Fund 2010) - http://www.kingsfund.org.uk/current_projects/gp_inquiry/dimensions_of_care/inequalities.html

Mariam Sbaiti

My name is Mariam Sbaiti and I was involved in the evaluation of the Chinese Hepatitis B clinic at the Chinese National Healthy Living Centre in Soho, while working as a junior doctor at 56 Dean Street (Chelsea & Westminster). I found the draft document on Hepatites in ethnic communities by the NSC very helpful and I was interested in submitting the results I found as part of the consultation.

The data involves a retrospective study of the HBV period prevalence in the 442 patients attending during the first year of the service (up to summer 2010).

I wondered:
- would we be able to submit these results?
- what is the deadline for submission of the data?
- I have not yet completed the write-up of the study. Would it be advisable to send the main outcomes first ie. overall prevalence and demographics? Or would you also need the raw data?

Thank you and kind regards,

Mariam SBAITI
Global Health Teaching Fellow
Imperial College

Reply from Dr Mackie

Dear Mariam,

Thank you for your contact. The UK NSC only really uses peer reviewed literature as we need to make sure our data is of the best. When will your work be published? If beyond the timescale for this decision then we would take it into account when we next look at it (usually three years hence unless something major has occurred in the world literature).

Looking at the consultation document though I think the major problem standing in the way of a screening programme is an understanding of how to access people from the relevant groups, acceptability and effectiveness of a whole screening programme rather than prevalence.

Thanks

Anne Mackie

Royal College of Physicians

Dear Dr Mackie

Re: Hepatitis B and Hepatitis C screening among ethnic minorities born outside the UK

The Royal College of Physicians (RCP) is grateful for the opportunity to comment on the above draft. We would like to make the following joint response.

Overall, we believe that the appraisal is fair and balanced and have no significant criticisms of the methodology or discussion.

The role of GUM is not mentioned in the document although clearly the specialty will have a significant role to play in any screening programme and contributes significantly already. The CEG/BASHH guidelines recommend screening for HBV in people from medium/high prevalence countries although not currently for HCV in ethnic minorities. In 2009 1251 new cases of HBV and 1481 new cases of HCV were diagnosed in GUM clinics in the UK (1224 and 1340 in England). This rate of diagnosis has been consistent for the last 10 years and in fact has risen in more recent years.

NICE's evaluation of HBV and HCV treatment has already shown cost-effectiveness and therefore opportunistic screening in situations such as GUM is clearly beneficial. The national screening committee will need to evaluate the cost effectiveness of more widespread screening before making any recommendations.

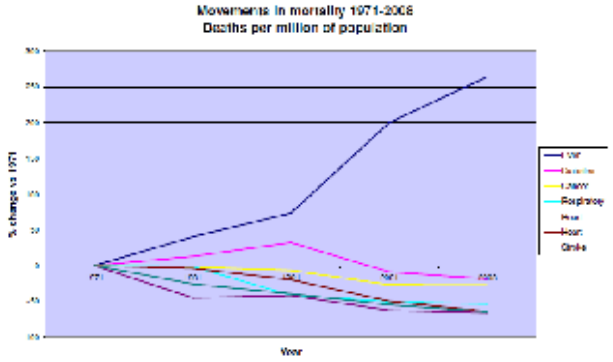
Yours sincerely

Dr Patrick Cadigan
Registrar

British Liver Trust response to:

Screening for hepatitis B and hepatitis C among ethnic minorities born outside the UK: A draft report for the National Screening Committee.

The British Liver Trust is the patient group for adult liver disease. The British Liver Trust aims to reduce the incidence of liver disease, and to help everyone affected by liver disease, through the provision of information, support and research. This document represents the views of the British Liver Trust as a charity for adults affected by liver disease.



Liver disease is the fifth biggest killer in the UK and the only one out of the five still seeing an increase. Patients are dying of the disease at a younger age than they were 20 years ago – a picture that stands in stark contrast to most other major developed nations, where death rates from liver disease are falling

Summary

Currently, the main risk factors for the development and progression of liver disease in adults are alcohol consumption, obesity and infection with hepatitis B or C viruses.

Hepatitis infection currently causes one quarter of the liver disease in England, but this proportion is likely to increase markedly within the next 10 years. Current best estimates suggest that anywhere between 190,000 and 350,000 people are infected with hepatitis C, but less than one-quarter of them are currently in contact with health services. The official 180,000 prevalence figure reported by the Department of Health in 2002 is questionable, and out-of-date. In 2008, the Hepatitis B Foundation UK estimated that there are 325,000 people in the UK with chronic HBV infection.

Despite this lack of service contact, notifications of hepatitis C infection have more than doubled over the past decade, rising from around 1,000 notifications per year at the turn of the century to 2,000 in 2006.

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However it is worth noting that notification of hepatitis C by doctors on clinical suspicion is not as robust a means of surveillance as laboratory testing.

According to the Health Protection Agency's sentinel surveillance study the number of people tested has increased each year from 2002-2007. A report from the British Association of the Study of the Liver (BASL) suggest that between 15 per cent and 20 per cent of individuals infected with hepatitis C might be expected to develop cirrhosis after approximately 20 years, with rates accelerated in those who drink excessive amounts of alcohol. This means that many people who were infected in the 1960s, 70s, and 80s are now presenting with symptomatic, severe liver problems, and projections suggest that the numbers of patients with end-stage complications of hepatitis C will continue to rise dramatically over the next 5 years.

Hepatitis B accounts for about a fifth of the reported cases of chronic hepatitis infections in UK[1]. There are around 1,300 new cases of acute hepatitis B reported in the UK each year – roughly three a day. In some people, acute HBV infection causes unpleasant, distressing symptoms. However, most patients with chronic hepatitis B do not realise that they have been infected until years later when they develop cirrhosis, end stage liver disease or liver cancer. For instance, in the report entitled, *'Hepatitis B: Out of the Shadows',* by the Foundation for Liver Research suggests patients with chronic hepatitis B (CHB) are some hundred times more likely to develop hepatocellular carcinoma than those who are not infected.

Overview

The British Liver Trust welcomes the opportunity to respond to the National Screening Committee's draft report on 'Screening for Hepatitis B and Hepatitis C among ethnic minorities born outside the UK'. As the only national charity for adults with liver disease, and a remit to promote liver health, the Trust firmly believes that the case for case-finding, identification and treatment all need to be reviewed in order to reduce viral hepatitis harm. There needs to be a much greater focus on identifying at 'risk groups', positively reaching out to them (and associated members of family) for screening and treatment. We are therefore particularly pleased to see within the proposed recommendations from the AGH that minority ethnic groups should be given the opportunity to get tested for viral hepatitis, and would endorse that case-finding activity needs to be implemented before the NHS is deluged with patients requiring a liver transplant or with decompensated liver disease.

We would wish to emphasise the need for systematic case finding, either at a national or local level. In the light of the potential move to GP commissioning we would call for this to be made as straightforward and cost effective as possible for implementation, with clear measures and outcomes. Whilst it is not mentioned in the draft, we understand that it is often a problem within ethnic minority groups that they are not always registered with a GP, so consideration should be given to how to best reach out to these groups, perhaps including a community setting.

Response

The British Liver Trust strongly believes proactive testing is needed and fully supports the recent recommendations from the report from the Department of Health's Advisory Group on Hepatitis (AGH 2009):

- Primary Care Trusts (or equivalent bodies) should arrange case finding for chronic HBV and chronic HCV infected individuals from minority ethnic populations in their area who were born in countries with a high or intermediate prevalence of HBV infection (as defined by the World Health Organisation (WHO) and ensure that there are care pathways in place for those who are found to be infected.

- Primary Care Trusts (or equivalent bodies) should arrange tracing and testing of all contacts in the UK of minority ethnic individuals testing positive for chronic hepatitis B or C infection. Such contact tracing should include family members (spouse, partners, grand-parents, parents, siblings, and children) and all individuals living in the same household. Contacts who are negative for evidence of HBV infection or immunity should be offered the HBV vaccination.

The Trust believes that there should be systematic case finding in high risk populations – in which health services identify high risk individuals and invite them to be tested. The strategies for case finding must be innovative and use previous examples of best practice in order to achieve excellent uptake of the tests.

A systematic approach to testing and GP registration should be considered for new immigrants entering the UK from countries with a high or intermediate prevalence of HBV infection, especially in the case of pregnant women, so that care pathways are in place to implement the current guidelines.Care should be given to also reach out to those groups which are not registered with GPS.

The cost of doing nothing

Viral hepatitis is an important health problem in the UK and therefore should have the appropriate resources, understanding and financial commitment to addressing it. End-stage liver disease is costly and a long-term view needs to be undertaken in the NHS and investment should be given to brief interventions and screening programmes. The Trust firmly believes that inaction is not an option. The burden of liver disease could increase sharply in the short to medium term, as people who contracted hepatitis 30 to 40 years ago become liver disease patients.

The cost to the NHS, and impact of risk factor non-recognition and lack of community preventive services could be severe. Modelling indicates that a person drinking above lower risk levels that is identified and counselled in primary care could cost the NHS as little as £40; while the same individual who is not identified and progresses to terminal liver cirrhosis could cost the NHS upwards of £21,000 over their lifetime. This example could also be used to aid the argument for screening for viral hepatitis. A dry blood spot (DBS) test, costs only £25, compared to the potential £21,000 treating terminal liver cirrhosis or an approximate £100,000 cost for a liver transplant.

Based on the figure (£21,000) estimated for treating terminal liver cirrhosis (as stated on page 5 in the DH commissioned report: Unmasking liver disease: the forgotten killer), and the figures given in the draft report (point 10, page 5, see below), a crude cost can be calculated for the potential cost of not screening for viral hepatitis.

> *Reasonable, but extremely approximate, estimates are that, among the target group of 3 million UK residents who were born in countries with high or intermediate prevalence of HBV infection, there may be:*
>
> - *120,000 individuals with chronic HBV, of whom 20,000 may develop cirrhosis in the next 20 years if not treated*
> - *30,000 individuals with chronic HCV, of whom 5,000 may develop cirrhosis in the next 20 years if not treated.*
>
> Point 10, page 5. Screening for Hepatitis B and Hepatitis C among ethnic minorities born outside the UK: A draft report for the National Screening Committee

By multiplying the number of individuals with HBV or HCV who may develop cirrhosis in the next 20 years by the cost of treating terminal liver cirrhosis, the cost to the NHS will be an estimated £525 million. Please note, this figure is only based on treating terminal liver cirrhosis, not liver transplantation.

With increased levels of obesity, diabetes and alcohol consumption nationally (varying often by ethnicity) these co-morbidity factors may exacerbate the problem – meaning these numbers might increase even further

£21,000 x 25,000 HBV (20,000) and HCV (5,000) individuals who may develop cirrhosis in the next 20 years if not treated

= £525 million

Support networks and translated information

Alongside a screening programme in ethnic minority groups, there needs to be fully integrated support networks and translated, reputable information. Liver patients are already marginalised by the availability and location of care from specialist hepatologists (few in number); therefore appropriate care pathways need to be implemented so that individuals proceed to treatment in a timely manner. Care should also be given to include new routes into the community to aim communication and understanding. Recent initiatives around breast cancer screening in the East End of London have shown that, whilst peer to peer messages and 'recruitment' have worked for the largely white population, for the Bangladeshi community, using a trusted Bangladeshi doctor to spread the message and highlight the urgency for screening, was more effective.

Communications through community elders, such as local Imams, and the effectiveness of HBV and HCV testing in mosques in Professor Graham Foster's study has been proven and is under further evaluation. This also in part attempts to ensure that the challenges of stigma within a community are also addressed.

Ongoing language and cultural support is very important, particularly given the challenges and long duration of HCV and HBV treatment. The dangers of people starting a course of treatment and then stopping due to the difficulties are well documented. In addition, this can make it more difficult, costly and sometimes less successful when tackling the virus a second time.

Outcome measures and data

A key learning from Professor Graham Foster's mosque study was that, although individuals were identified as having viral hepatitis, ensuring they received further follow up tests and advice was difficult. Additionally, hard outcomes from the DH's South Asian awareness campaign were not evident. For instance, if a caller was advised to visit their GP following a screener questionnaire, this was regarded as a 'referral'. Unfortunately there was no system in place which monitored and captured whether the individual did actually go to their GP to be tested for viral hepatitis. Systems for surveillance and monitoring of a patient's journey needs to be implemented in order to prove hard outcomes of the success of the screening as well as driving more people into treatment and signposting appropriate advice and support.

Data is consistently a challenge in the area of HBV and HCV (as well as liver disease generally) and we would call for strong underlying data to be collated as part of this to inform the health economics and lever for effectiveness of future programmes.

Conclusion

Professor Foster's study suggests that as many as one in 20 people born in Pakistan and living in England have chronic viral hepatitis. The Trust believes that this evidence provides a strong justification for a policy of case finding in this population.

Opportunistic screening in mosques and other community settings can only go so far in identifying people with viral hepatitis therefore a **systematic national** approach to case-finding needs to be implemented.

The **current systems also need greater systematising**, as we understand that even the current mother to baby programmes show that full vaccination schedules are not always followed, and family and friends screening is very patchy.

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Key considerations for systematic case finding in high risk populations:

1. Support networks, counselling and viral hepatitis information should be provided in the language of origin and using community channels as well as primary and secondary care
2. Screening programmes should be ongoing, and a 'one-hit wonder' simply won't be effective
3. Previous screening initiatives have targeted the male populations in these ethnic groups. A programme needs to be developed to target females and children to ensure they are given the opportunity to get tested
4. Systems for surveillance and monitoring of the patient's journey needs to be fully implemented prior to any screening programme, so that it can be proven to have an effect and individuals are not left with a diagnosis but no route into treatment/further health advice and support
5. A systematic approach to testing and GP registration should be considered for new immigrants entering the UK from countries with a high or intermediate prevalence of HBV infection, especially in the case of pregnant women, so that care pathways are in place to implement the current guidelines.
6. Care should be given to also reach out to those groups which are not registered with GPS
7. Vaccination schedules for babies born to HBV mothers should be reviewed as there is some evidence to suggest that some do not receive the full vaccination course, in particular the final and fourth vaccination when they have reached their first birthday. This issue is not exclusive of ethnic minority communities; however it should remain a consideration for this review.
8. Capacity for informing, diagnosis and treatment within primary care should be created to enable this, and measures and incentives for GP commissioners and/or PCTs would be put in place to ensure the success of the programme.
9. Not all treatment is in primary care, treatment of more difficult cases will take place in secondary and tertiary care settings, with support from primary care, there should be a joined up approach across all stakeholders, irrespective of where the patient is treated.

Further information

For further information please contact Sarah Matthews on 01425 481333 or sarah.matthews@britishlivertrust.org.uk

[1] The Rising Curve of hepatitis B. The Hepatitis B Foundation. 2008.

Annex B

Key research questions on systematic screening of ethnic minorities for Hepatitis B Virus and Hepatitis C Virus

1. What is the sensitivity, specificity and acceptability of the following 2-step process for identifying which GP-registered individuals were born in a country where Hepatitis B Virus (HBV) prevalence ≥ 2%:
   - Use the best available software package (currently the Experian 'Origins' package seems the best bet) to identify individuals with names which indicate they may have been born in a country where HBV prevalence ≥ 2%.
   - Write to all those who are flagged up by step 1, asking them to state their country of birth.

   It may be challenging to answer this research question, because we don't have gold-standard data against which to evaluate the process. The best answer available may be one from the (self-selected) population of people who are willing to respond to a letter asking where they were born.

2. How does systematic screening (following the approach outlined above) compare with opportunistic screening in primary care, in terms of acceptability and number of new diagnoses of HBV and Hepatitis C Virus (HCV)?

3. In a systematic screening programme, what proportion of UK residents who were born in a country where HBV prevalence ≥ 2% will accept an offer of testing for HBV and HCV?

4. What is incremental cost-effectiveness of systematic over opportunistic screening for HBV and HCV in individuals who were born in a country where HBV prevalence ≥ 2%?

   In addition to all the variables that are typically included in existing C-E studies, this needs to incorporate the following:

   - effectiveness and costs of identifying and inviting the target population
   - proportion of HBV-positives who receive anti-virals (Graham Foster estimates 20% initially, with a further 30% over the next 20 years)
   - effect of antiviral therapy on health-related quality of life in HCV
   - emigration of immigrants after screening & treatment (liver disease avoided in these individuals will not represent cost-savings to the NHS)
   - impact of broadening criteria to include 4 million people who originate from, but were not born in, countries with > 2% HBV prevalence.

Other questions that are not yet adequately answered, but are less critical to the policy decision

5. How many cases of HBV will be avoided by vaccination of household and sexual contacts of cases detected by screening foreign-born ethnic minorities for HBV?