HEPATITIS C
IN THE SOUTH ASIAN COMMUNITY:
A BEST PRACTICE CASEBOOK
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INTRODUCTION
This casebook aims to support commissioners to deliver hepatitis C services, which focus on the South Asian Community, by identifying a series of best practice case studies and making recommendations as to how they might be replicated across the NHS. These case studies span different aspects of the patient pathway including: establishing prevalence, working with the local community, raising awareness, engaging General Practitioners (GPs) and delivering diagnosis and testing services. It is hoped that by following these steps, commissioners will be in a position to evaluate and redesign their services to ensure South Asian people at risk of the hepatitis C virus are identified and then initiated onto appropriate treatment.

This is particularly important as the hepatitis C landscape in the UK is changing rapidly. During 2015, a number of hepatitis C treatments were approved by The National Institute for Health and Care Excellence (NICE) and the establishment of the new Operational Delivery Networks have developed a new model for service delivery. It is therefore a timely moment for the NHS to consider the effectiveness of its services, particularly for South Asian patients who can face a number of specific cultural challenges when accessing healthcare.

This report and the case studies within were determined and ratified by a working group of hepatitis C experts. Bristol-Myers Squibb would like to thank the following individuals for their involvement in this project: Professor Aftab Ala (Consultant in Hepatology and Gastroenterology, Royal Surrey County Hospital NHS Foundation Trust); Andrew Langford (Chief Executive, British Liver Trust); Imam Yunus Dudhwala (Head of Chaplaincy and Bereavement Services, Barts Health NHS Trust); Grace Everest (Policy and Public Affairs Manager, Hepatitis C Trust); Valerie Ross (Lead Pharmacist, Barts Health NHS Trust); and, Safina Shahin (Blood Borne Virus Champion, IRIS Reading).

Whilst the content of this report focuses on optimising hepatitis C services, the working group considered that the identified case studies could also provide a model for South Asian specific services across a range of conditions and blood borne viruses including hepatitis B or tuberculosis.

HEPATITIS C IN THE SOUTH ASIAN COMMUNITY
According to Public Health England, the most recent national estimates suggest that around 214,000 people are chronically infected with hepatitis C in the UK. The prevalence rate for hepatitis C amongst adults in England is thought to be 0.4% (160,000 adults, 2005 data), although in Scotland prevalence is estimated to be higher, at 0.7% of the population (36,700 people, 2014 data). If left untreated, hepatitis C can lead to end-stage liver disease, cirrhosis of the liver, hepatocellular carcinoma and the need for liver transplantation. Between 2004 and 2013, hospital admissions from hepatitis C-related hepatocellular carcinoma and end-stage liver disease rose from 950 to 2,658. Over the same time period, deaths have risen from 190 to 424. Between 1996 and 2014, the number of liver transplants carried out in the UK inpatients with hepatitis C-related disease rose from 45 to 175.

One of the major at-risk groups for this virus are people of South Asian origin. Various studies have found that prevalence of hepatitis C amongst this population is considerably higher than the rest of the population. Public Health England’s Hepatitis C in the UK 2015 report shows that hepatitis C infection is higher amongst blood donors of South Asian origin than from other groups. Similarly, studies in Glasgow have also found that prevalence in the city’s South Asian community was as high as 3.1% amongst people born in Pakistan. This can be attributed to the high infection rates in countries such as Pakistan. Modes of transmission can include receiving healthcare whilst in South Asia in a setting with sub-optimal sterilisation procedures. Around 45% of cases of hepatitis C in the UK are thought to be the “genotype-3” strain of the virus, which the World Health Organisation has also declared to be endemic in South East Asia.

ENDORSEMENTS
This report has been produced by Bristol-Myers Squibb Pharmaceuticals Ltd and has been endorsed by The Hepatitis C Trust and the British Liver Trust

[Endorsement logos]
In addition to the higher prevalence of hepatitis C in this population, the South Asian community also faces particular challenges in accessing services and care. These challenges were outlined in The Challenge of Hepatitis C in the South Asian Community report, which was published in January 2015, following a Parliamentary meeting which was organised by Bristol-Myers Squibb Pharmaceuticals Ltd, who assisted in the production of the report. This report identified a number of recommendations for existing services to help overcome the challenges faced by the South Asian Community:

UNDERSTANDING CULTURAL SENSITIVES: Too often, hepatitis C services are provided in settings such as sexual health clinics and Terence Higgins Trust facilities. Hepatitis C services should be moved into more culturally appropriate settings such as religious institutions, where people feel more comfortable about coming forward to receive treatment.

WORKING WITH RELIGIOUS GROUPS: Education, diagnosis and treatment is best delivered if it is administered through community and religious groups. Religious settings, such as mosques and gurdwaras, provide convenient locations to provide information to large proportions of the South Asian community and also to provide testing and other services in an accessible way. Religious and community groups also have an important role in helping to reduce the stigma associated with hepatitis C.

COMMUNITY CHAMPIONS: Awareness of hepatitis C is one of the major barriers preventing South Asian patients from accessing treatment. Therefore, one of the most effective ways of dealing with this is through the creation of a series of “community champions”. These champions would help to raise awareness of hepatitis C and could include former patients as well as specialist nurses with links to the local community. The role of these champions would be to raise awareness of the risks of hepatitis C, prevent future transmission of the disease and help people to understand the potential of emerging treatment options to cure the disease with reduced treatment duration and side effect profile. These champions could help to run support groups for patients and their families to learn more about the consequences and implications of the virus.

IMPROVING AWARENESS: Central to improving diagnosis and treatment rates will be the use of effective awareness raising campaigns for patients, GPs and commissioners. This will be important to help patients understand the benefits of new treatment options. Similarly, it is important that GPs and commissioners understand the importance of identifying and treating people with hepatitis C. Left untreated, the virus can cause liver cirrhosis or liver cancer which can not only prove fatal, but increases the financial burden upon the NHS.

Having established the barriers facing South Asian patients, it is important to understand how responsibilities are divided under the new Operational Delivery Network (ODN) system.

SERVICE REDESIGN FOR HEPATITIS C – THE NEW COMMISSIONING LANDSCAPE

In October 2015, NHS England published a new ‘service specification’ for hepatitis C. This document provides a framework for how hepatitis C services in England should be structured. The service specification references the need to develop “tailored services to meet the needs of specific vulnerable groups” including “migrant populations”.

Whilst it is not prescriptive about the way such services are designed, it sets out a rationale for why services should be optimised:

• The long term cost savings, for primary and secondary care, associated with treating hepatitis C now.
• The possibility of significantly improved patient outcomes, particularly with the availability of new treatments.
• The possibility of reducing onward transmission of the virus.

OPERATIONAL DELIVERY NETWORKS

Operational Delivery Networks are led by a specialist centre known as the ‘Specialist Hepatitis C Host Organisation’ who is responsible for managing treatment decisions and prescribing through an expert multi-disciplinary team. However, the networks also operate a “dispersed delivery model” which encompasses any service undertaking hepatitis C testing or delivering subsequent care. According to the Casebook Working Group, services for the South Asian Community, could include the establishment of education or testing services in a mosque or gurdwara. In the Service Specification, NHS England states its belief that such services will be “easier to set up as part of formal clinical networks than with uncoordinated local commissioning”.

Under this system, NHS England is responsible for covering the cost of drugs required for treating hepatitis C infection, as well as the resource and facilities necessary to ensure appropriate management of all patients referred within a specialised service. Members of the working group highlighted how this was an important consideration: with funding for treatment covered by NHS England specialised services, there should be no financial disincentive for local commissioners to undertake awareness, testing or diagnosis campaigns, to identify South Asian patients at risk of hepatitis C.
IDENTIFYING BEST PRACTICE IN THE SOUTH ASIAN COMMUNITY

ESTABLISHING LOCAL PREVALENCE AND NEED

One of the objectives within the service specification is to establish a managed network of services which are responsive to local epidemiology and prevalence. The Working Group argued that it is therefore important that services are designed according to the users most at-risk in that locality. For instance, areas with a large South Asian population will want to analyse whether services are designed and developed according to the needs of that population group.

The below case study highlights the importance of establishing local prevalence for the South Asian community.

GLASGOW – COMMUNITY BASED SURVEY AND LABORATORY SURVEILLANCE


A team of clinicians in Glasgow understood that hepatitis C and B prevalence in the South Asian community was thought to be high and that early diagnosis and treatment was key to high quality outcomes. However, they had no data on the prevalence amongst Glasgow’s South Asian community.

To rectify this, a community-based survey recruited individuals at six mosques and four community centres serving the South Asian community during 2009-2010; most participants had never been hepatitis C tested.

The study had 1,288 participants, 2.6% of whom tested hepatitis C positive. The prevalence ranged from 0.6% in people born in the UK to 3.1% of people born in Pakistan. The odds of testing positive were significantly higher if the participant had surgery in South Asia, or had medical or dental treatment or injection there.

Based on the results of this study and a laboratory-based study, the clinicians concluded that an estimated 38% of hepatitis C-infected South Asian people living in Glasgow remained undiagnosed as of 2010.

CONCLUSIONS:

Based on these case studies, the Working Group concluded that:

- A focus on hepatitis C in the South Asian Community can prevent disease progression and save lives. Left untreated, the virus can cause liver cirrhosis or liver cancer which can not only prove fatal, but increases the financial burden upon the NHS.

- It is important that any strategy identifies the specific prevalence and need in that area. This will ensure that a robust business case can be developed, which escalates activity and targets resources most effectively across various aspects of the patient pathway.

ENGAGING COMMUNITY AND RELIGIOUS GROUPS

Building strong foundations both with local South Asian community leaders and local clinicians is an important determinant of success. Engaging community and religious groups helps to break down the stigma associated with the virus through active consultation and can help determine how services should be designed.

ROYAL SURREY COUNTY HOSPITAL NHS FOUNDATION TRUST AND UNIVERSITY OF SURREY – COMMUNITY SPECIFIC FOCUS GROUPS


Across the Operational Delivery Network led by the Royal Surrey County Hospital NHS Foundation Trust and University of Surrey, a number of strategies have been developed to improve hepatitis C services for the South Asian Community. This has included a number of projects which aim to raise awareness of hepatitis B and C, to offer testing to at-risk groups from the South Asian and Nepali migrant communities, and inform the evidence base on the prevalence of hepatitis B and C in these groups.

For instance, it was identified how the Royal Surrey County and Frimley Park Hospitals in Surrey, which are covered by this ODN, serves a large primarily Pakistani, South Asian community. In the Woking area, up to 30% of the local population are of Pakistani origin, and the neighbouring area of Aldershot is also home to the UK’s second largest Nepali community. To reflect the number of at-risk patients, the hospitals identified improving awareness of viral hepatitis and diagnosis rates amongst the South Asian community as a key priority.

In developing this, the service designers recognised that the Nepalese community had, predominantly, recently arrived in the UK and little was known about their attitudes to, and awareness of, liver disease and hepatitis C. In order to lay the groundwork for their later work, the hospital staff conducted focus groups with members of the local Nepali and Pakistani community.

Overall, 22 members of the Nepali community attended the focus groups, which were divided by age and gender. They found that there was a limited understanding of both the causes and treatment of hepatitis C in this community. Views expressed ranged from the belief that hepatitis C was genetic and not communicable, or that it was spread via food or due to witch doctors. There was also a belief that herbal medicine was the best treatment for hepatitis C. Younger members of the community also expressed considerable concern about the stigma associated with hepatitis C, linking the virus with alcohol use and prostitution.

The focus groups also identified issues relating to functional illiteracy, which caused difficulties in engaging the community. These findings informed the design of services and later strategies, such as the use of word of mouth advertising, in place of written material. The specific strategy is outlined in more depth later in this document.

Working group attendees highlighted how a number of related projects focusing on tackling viral hepatitis in the South Asian Community are continuing across the ODN and Surrey more widely.
INCREASING UPTAKE OF HEPATITIS C TESTING IN THE
PAKISTANI POPULATION IN READING, ENGLAND

D. Linzey, S. Shaheen

There has been an increase in the transmission and diagnosis of hepatitis C in Reading’s significant South Asian population. This posed a particular problem for the local NHS, which found that it had been previously unaware of the extent of the problem in this population and that there were significant barriers to effective care, including a distrust of health services and social stigma associated with blood borne viruses.

In response to these challenges, a group of clinical nurse specialists developed a ‘community champions’ model to raise hepatitis C awareness within the South Asian community and reduce the stigma associated with blood borne viruses, whilst encouraging testing and entry into treatment.

The “BBV Champions” model that the group developed was built on a concept developed in rural Africa to tackle HIV infection. A group of eight Pakistani housewives were identified and trained to be “Champions” for their community. This group of “Asian Ladies”, as they became known, managed to test 300 people in the Reading area in the first 18 months they were active. Of the 300 people tested, 8 were identified as having hepatitis C and 6 have suddenly achieved a Sustained Virological Response through treatment. The clinical nurse specialist who developed this scheme believes none of these patients would have been identified without it.

The “BBV Champions” model, also known as the “Asian Ladies”, has since been recognised nationally due to its success and other providers have expressed an interest in adopting it elsewhere. The advantage of this model is that it does not require the presence of one leading clinician, and that community champions can continue to disseminate information and advice autonomously of the service which trained them, once they have received this training. It also requires little by way of financial resources to initiate and operate. However, Safina Shaheen who attended the working group, added that the service can only be truly successful with continued support and engagement with NHS services.

CONCLUSIONS:
According to the Casebook Working Group:

- A successful service should look to engage the local community in the design and delivery of services at the earliest possible opportunity. This will help identify specific problems, engage relevant individuals within the service and lay the groundwork for future success.
- It is important to develop local champions from religious institutions like mosques or gurdwaras or from within the local community. As the Reading case study shows, this plays a key role in ensuring people engage with local services.
- However, it is important that community champions are not just restricted to within the South Asian Community - any qualified and enthusiastic local figure can make a big difference.
- The development of community champions is not only considered to be effective but financially viable, requiring little investment to initiate and operate. In part, this is due to the fact that a prominent clinician does not need to be involved in this programme, with the champions themselves being tasked with independently disseminating information and advice.
TACKLING THE STIGMA OF HEPATITIS C

As was highlighted in the *Challenge of Hepatitis C for the South Asian Community* report, one of the main problems for the South Asian community is a lack of awareness about hepatitis C. In particular, there is insufficient knowledge around how hepatitis C is transmitted, the symptoms and implications of having the disease. This lack of awareness and resulting stigma, can often act as a barrier to diagnosis and later treatment.

To combat this, it is important that community specific awareness raising projects take place. The following two examples show different ways of how this can be achieved. One, based in London, brought a range of stakeholders together to create online resources to dispel myths and stigma around hepatitis C. The other, in Manchester, mobilised community leaders to raise awareness about the disease.

MASLHA – ‘UNDERSTANDING HEPATITIS B AND HEPATITIS C’

Recognising the low knowledge levels of hepatitis B and C in the East London Pakistani community, social enterprise Maslaha created a new health resource to encourage early diagnosis in primary care.

Maslaha was set up is to improve the conditions that create inequalities in Muslim communities. Its work covers a range of issues including health, education, the criminal justice system, gender equality, and the arts. Maslaha found that some hepatitis B and C patients of Pakistani origin were being turned away by GPs who considered them ‘not at risk’. At the heart of this was a lack of understanding about the diseases, and cultural risk factors including circumcision and shaving in preparation for the Hajj, by both the East London Pakistani community and GPs.

With funding from Barts Charity, the charitable arm of Barts Health NHS Trust, Maslaha worked with the Blizzard Institute at Queen Mary, University of London (QMUL), the Hepatitis C Trust, patients, imams and scholars, and GPs on a campaign to encourage British Pakistanis to “understand, prevent and get tested for hepatitis B and C”.

The centrepiece of the campaign is the *Understand Hep B and C* website, which hosts two 11 minute videos, one in English and one in Urdu, featuring Professor Graham Foster of QMUL, Shabana Begum of the Hepatitis C Trust, and Imam Yunus Dudhwala, Head of Chaplaincy at Barts Health NHS Trust. The films provide a basic overview of the hepatitis B and C viruses, including their transmission, their potential harm, the treatments available both to cure and stop the viruses from progressing, and the specific risk to Pakistanis. This information is combined with cultural and religious references to help overcome stigmas and encourage Pakistanis to get tested and seek treatment. Maslaha also produced posters and DVDs which encapsulate the messages of the films.

The website provides a page with information specifically tailored to doctors, referencing NICE Public Health Guidance on testing people at increased risk of hepatitis B and C infection, as well as the NICE Quality Standard for reducing the spread of hepatitis B. This page also links to the free online course developed by the Royal College of General Practitioners on hepatitis B and C Detection, Diagnosis and Management.

There is also a page with information specific to patients, explaining how to get tested and encouraging them to think about possible times they may have been at risk of infection during visits to Pakistan.

Additionally, the website provides a page with the latest research findings on hepatitis B and C worldwide, within the UK and South Asian communities. This page also details eight specific challenges facing both Pakistani patients and the clinicians treating them, including a language-based issue of many Pakistanis using the same Urdu word for both jaundice and hepatitis and therefore confusing the two conditions.

Since its launch in summer 2014, Maslaha’s hepatitis resource was utilised as a reference by Redbridge CCG, which urged residents born in Pakistan to get tested on World Hepatitis Day (28th July) 2014. Its English and Urdu films were also mentioned as a useful resource in Public Health England’s *Hepatitis C in the UK 2015 Report*, which said: “Such films can be particularly useful as they combine medical and cultural guidance to help learn about infection and how best to get tested.”
GREATER MANCHESTER HEPATITIS C STRATEGY – HEPATITIS C IN THE SOUTH ASIAN COMMUNITY

From April 2012 to March 2013, the Black Health Agency (BHA) and Islamic Society of Britain (ISB) worked in partnership with the NHS to deliver a hepatitis C awareness raising project in the South Asian Communities of Greater Manchester.\textsuperscript{65}

This initiative was commissioned in January 2012 by the Greater Manchester Hepatitis C Strategy, which identified “working with NHS partners to evaluate testing methods among the South Asian community” as a priority in its 2010 – 2013 plan\textsuperscript{66}. The project consisted of a series of information sessions delivered by GP representatives from the ISB and staff from the BHA support project. These sessions were presented in English, Urdu and Punjabi and delivered in eight mosques, as well as at the annual Manchester Asian Mela.\textsuperscript{67}

First, the ISB and BHA would inform the Primary Care team and relevant minority ethnic organisations in the local area about the work that was being undertaken and discuss the content and possible collaboration. The information sessions themselves were not identical in each area, but followed a similar format. They were delivered between prayer times to gain access to worshippers coming to pray. Participants were first asked to complete a short questionnaire on hepatitis C to ascertain their knowledge ahead of the session, and then asked to complete it again at the end to see how their knowledge had improved. The main part of the session consisted of a slide presentation with clear visual material on hepatitis C transmission, symptoms, treatment and the effects of late diagnosis and non-treatment.\textsuperscript{68}

Following the slide presentations, participants were divided into groups to consider questions posed by the session’s facilitators. Participants were encouraged to express their opinions, doubts or fears about hepatitis C at this time. After the group work, expert patients described their personal experiences of hepatitis C, which proved to be a powerful and emotive way of helping attendees understand the condition. Finally, participants were given a pack with information in English and Urdu. The pack also included a flier with Quranic references to emphasise the importance of reading it and a tear-off slip that could be given to a GP to request a hepatitis C test.\textsuperscript{69}

Altogether, this initiative delivered information sessions to a total of 396 individuals from the target communities, of which 170 were women and 226 were men. The organisers found that delivering the information sessions in mosques helped them gain access to a higher number of men than was usually possible in other community sessions. They also found that the gender segregated nature of the mosque helped female attendees feel more comfortable about asking questions.\textsuperscript{70}

Increasing Uptake of Hepatitis C Testing in the Pakistani Population in Reading, England

D. Linzey, S. Shaheen

As previously identified, one of the successes of this project was the recruitment of a number of community champions. To complement this, the service also identified a number of settings, often not traditionally associated with the distribution of healthcare materials, in which hepatitis C awareness could be raised.

For example, information leaflets were displayed in travel agents who specialised in travel to South Asia and for pilgrimages such as the Hajj. These leaflets provided information about the virus, risk of transmission and the importance of getting tested.

Similarly, Safina Shaheen who was present at the working group meeting highlighted how they utilised other appropriate settings, such as community pharmacies to distribute information and in some cases provide on-site testing facilities.

CONCLUSIONS:

Based on these case studies, the Working Group felt that stigma could best be tackled by:

- One of the main barriers to diagnosis or treatment is the stigma associated with having hepatitis C. For instance, South Asian patients often express concern that having the virus would have a negative impact on their marriage potential, due to the fact they would be considered to be ‘promiscuous’ or ‘unclean’.
- Any project involving the South Asian community should aim to dispel myths about the disease, explaining transmission risks, whilst facilitating ‘word of mouth’ awareness raising.
- This can be done in a number of ways, either online or through more traditional methods, such as written literature or word of mouth. However, content must be community specific and delivered in conjunction with a community or religious group.
- As the work conducted in Reading demonstrates, there are opportunities to raise awareness across a range of different settings, including travel agents which specialise in trips to high prevalence areas.
- According to the Working Group, it is also important that commissioners develop differing strategies for targeting men and women – for instance it was felt that testing in mosques was more likely to benefit men. This is because a higher proportion of Muslim women tend to pray from home, often due to the pressures of childcare. However, it was suggested that more women pray at mosques during the month of Ramadan, so any outreach is likely to be more successful during this period. Outside of Ramadan, in order to improve testing and treatment rates amongst Muslim women, it is important to explore holding these events at other facilities such as community centres, events and groups. Similar flexibility can often be required for the younger generation, who can find regular attendance at mosques incompatible with the pressures of work.
BUILDING CLINICAL SUPPORT

Whilst any successful campaign should look to engage the local South Asian community, it is also important to ensure a joined-up approach is developed, with GPs and other clinical figures engaged throughout the process.

The Working Group identified that, in particular, GPs have a key role in terms of identifying at-risk patients, encouraging them to receive diagnosis and if relevant, referring them to a specialist for treatment. Similarly, they can play a key role in the setting up and delivery of Hepatitis services for the South Asian such as sharing information on new registrations in the UK from prevalent countries. One way of achieving this might be to engage with travel nurses would can also provide preventative information to people visiting countries which have a greater prevalence of Hepatitis C.

The below examples demonstrate how and where this collaboration can take place and the results which this can achieve.

BEDFORD – HELPING HEALTH PROFESSIONALS IN BEDFORD REACH OUT TO THE SOUTH ASIAN COMMUNITY

Opal Greyson

Opal Greyson, a Viral Hepatitis Specialist Nurse working in Bedford, recognised that hepatitis C was an issue amongst the South Asian community in her local area. In particular, there was a low level of awareness about the disease in the South Asian community in Bedford, and a lack of access to testing as well. In general, this had made it difficult to assess the prevalence of hepatitis C in the area.

Opal undertook a project to improve awareness of hepatitis C amongst local healthcare professionals, including nurses and GPs, and Bedford’s South Asian community. Initially, she joined forces with the Hepatitis C Trust to bring a testing van to Bedford, to begin to raise local awareness of the disease. This took place around World Hepatitis Day and testing was offered at the same time. However, feedback received during this event informed Opal and the team that a lack of information about hepatitis C and current testing facilities were discouraging people in the South Asian community from seeking advice and diagnosis.

Following this, Opal began to develop relationships with community religious leaders in order to gain greater access to the South Asian population in Bedford. She was invited to address worshipers at local mosques and Gudwaras. This allowed Opal to address, on certain occasions, more than 1,000 people at a time to raise awareness and dispel myths around hepatitis C. During these events, Department of Health-endorsed information leaflets were distributed.

Having developed a relationship with these organisations, Opal began to attend Friday prayers at other mosques and set up information stalls. During these events, GPs were on hand to encourage worshipers to seek testing. Finally, Opal was eventually able to deliver oral testing at religious venues and at local GP surgeries. Through engaging clinical representatives such as GPs, this encouraged a much greater uptake of testing amongst the South Asian community.

Overall, the project was considered to be a success not just for the number of people treated and diagnosed but also due to the relationships built between the NHS and the South Asian community and the increased availability of information regarding hepatitis C. However, whilst a lack of resources limited the reach of this project, it demonstrates the benefits of a community – focused approach to hepatitis C awareness raising and testing that could be replicated more widely.

GREATER MANCHESTER – WORKING WITH NHS PARTNERS TO EVALUATE TESTING METHODS

As previously identified, the ISB and BHA initiative in Manchester was commissioned as part of the Greater Manchester Hepatitis C Strategy, which identified “working with NHS partners to evaluate testing methods among the South Asian community” as a priority in its 2010 – 2013 plan.

The success of this project therefore depended on building local clinical support.

As a first step, the ISB and BHA would inform the Primary Care team and relevant local minority ethnic organisations about the work that was being undertaken and discuss possible collaboration. The information sessions run in local mosques were then delivered by GP representatives from the ISB with the support of staff from the BHA. Information session participants were given a pack with information in English and Urdu, which included a tear-off slip that could be given to a GP to request a hepatitis C test.

The project was generally found to be successful in forging new links between interested GPs and other organisations, and in correcting some commonly held myths about hepatitis C.

CONCLUSIONS

According to the Working Group:

• Services deliver more effective results when they are joined-up, encouraging primary care practitioners to work collaboratively with community champions and specialist clinicians.

• In particular, GPs have important role in terms of identifying at risk patients and ensuring they receive diagnosis and if relevant treatment and support.

• By working with community champions and patient representatives, GPs can help to dispel the myths around hepatitis C and provide valuable clinical perspectives.
TESTING AND DIAGNOSIS

In order to help identify and treat hepatitis C in the South Asian community, it is important to ensure specific measures to test and diagnose patients are developed. In order for this to be effective, any such measure should be delivered in a setting appropriate to that community, which enables them to receive diagnosis discretely and efficiently. This could either be delivered through a dry-blood spot or saliva test and there a number of successful schemes which illustrate this:

NORTH EAST OF ENGLAND – DRY BLOOD SPOT TESTING PILOT SCHEME


Physicians based in Newcastle and Sunderland undertook a pilot scheme to introduce targeted testing for hepatitis B and C for the South Asian community across the North East of England. This followed an earlier, similar, pilot for the Chinese community which focused predominantly on testing for hepatitis B. The pilot scheme was an attempt to apply AASLD (American Association for the Study of Liver Diseases) guidelines on targeted screening for these viruses to the UK, where there are no similar guidelines. The study noted that there are also targeted screening guidelines in place via the European Liver Patients Association.xxvi

The pilot scheme invited members of the North East’s South Asian community to attend screening sessions at either a mosque in Newcastle or at the Sunderland Bangladeshi Community Centre. At these sessions, attendees were administered dry blood spot tests. Those who tested positive were advised to undergo further confirmatory testing and to be referred for specialist assessment and care.xxvi

Overall, 329 people were testing across four screening sessions. The majority of those tested (75%) were male and 49% were born in Bangladesh, with 36% born in Pakistan. Of those tested 14% were born in the UK and 1% of those tested were HCV-positive, all of whom were born in Pakistan. This equates to a prevalence of 3% amongst Pakistani people tested.xxvi

The authors of the study believe that the results shown provide evidence for a full targeted case finding programme for both hepatitis B and C subjects born in South Asia.xxvi

ROYAL SURREY COUNTY HOSPITAL NHS FOUNDATION TRUST AND UNIVERSITY OF SURREY - COMMUNITY TESTING


Following the establishment of patient focus groups (as identified earlier in this document), Frimley Park Hospital offered dry-blood-spot testing for hepatitis B and C, with those who tested positive referred to the hospital for treatment.xii

Altogether, 219 members of the South Asian community (89% of Pakistani origin) were tested in mosques between 2011 and 2012. Of these, 75% of these were male, and the mean age was 45 years.xii The programme identified eight hepatitis B cases and four hepatitis C cases. All positive cases were first generation migrants who had a shorter length of stay in the UK. The study identified a chronic viral hepatitis prevalence rate of 3.6% in the South Asian community.xii

However, the initiative’s most significant result was in the numbers tested within the Nepali community, a group for whom there was little pre-existing data on hepatitis C prevalence. The Nepali study tested 508 individuals between 2013 and 2014. The study found 62 individuals to be hepatitis B positive and one person to be hepatitis C positive. All patients who tested positive were first generation migrants, and the hepatitis B cases were typically older individuals who had spent less time in school. The study identified a chronic viral hepatitis prevalence of 0.6% in the Nepali community.xii

CONCLUSIONS

• The Working group believe that some useful conclusion can be drawn from these case studies, such as:
  • It is important that at-risk patients are tested for hepatitis C. Proactive testing programmes can help to find patients before their condition progresses.
  • As the above case studies demonstrate, there is potential to combine hepatitis C testing programmes with other blood borne viruses such as hepatitis B.
  • Following a positive diagnosis, the patient can be referred for appropriate treatment. Under the current system, NHS England is responsible for covering the cost of drugs required for treating hepatitis C infection, as well as the resource and facilities necessary to ensure appropriate management of all patients referred within a specialised service.
THE SOUTH ASIAN COMMUNITY – THE NEXT STEPS

now approved by NICE, there is an opportunity to ensure that can be combated and at-risk individuals encouraged to engage community figures, ensuring that any stigma around the virus to diagnosing and referring patients for appropriate treatment.

It is clear that any successful project will need to look needs. It is important to engage local religious and community figures, ensuring that any stigma around the virus can be combated and at-risk individuals encouraged to engage with NHS services. Similarly, it is important to engage the clinical community within this and GPs can play an important role in identifying at-risk patients. With a number of new treatments now approved by NICE, there is an opportunity to ensure that more patients from this community can clear the virus.

APPENDIX

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