Improving Awareness of Chronic Hepatitis C in Ethnic Minority Groups from South Asia in Greater Manchester 2012 – 2013

Commissioned by
Greater Manchester Hepatitis C Strategy (GMHCS)

Abstract

This is the final report of the BHA Hepatitis C Project delivered in partnership with the ISB (Islamic Society of Britain) implemented between April 2012 and March 2013. It shows that during its lifespan the project engaged with the south asian communities in Manchester to raise awareness of hepatitis c. The report illustrates the effectiveness of the project, the types of presentation used and the planning and resource creation that were required including examples of participant feedback.

Keywords: Hepatitis C, South Asian Communities, awareness, presentations, resources.
Improving Awareness of Chronic Hepatitis C in Ethnic Minority Groups from South Asia in Greater Manchester

Jan 2012 - March 2013

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1. Aim of the Project

This project was commissioned in January 2012 by the Greater Manchester Hepatitis C Strategy (GMHCS) to work in partnership with the National Health Service (NHS) and the Islamic Society of Britain (ISB) to raise awareness of the Hepatitis C Virus, transmission routes and risks, symptoms and treatment among South Asian communities living in Greater Manchester. In addition, the project was commissioned to increase awareness of secondary prevention of Hepatitis C among people from South Asian communities

1.1 Introduction

According to information available through the NHS website, “Hepatitis C is a virus that can infect and damage the liver. You can become infected with Hepatitis C if you come into contact with the blood or, less commonly, body fluids of an infected person. In most cases, Hepatitis C causes no noticeable symptoms until the liver has been significantly damaged. When symptoms do occur, they are often vague and can be easily mistaken for another condition. Symptoms include: flu-like symptoms, such as a high temperature and loss of appetite, feeling tired all the time (and) depression. Because of this, many people remain unaware that they are infected by Hepatitis C.”

Information regarding the extent of viral hepatitis in ethnic minority groups in the UK is currently limited. However, data from the World Health Organisation (WHO), and other sources, indicates that chronic Hepatitis C Viral infection (HCV) is common in many underdeveloped countries. Studies in Bangladesh and Pakistan show that the prevalence of HCV is between 0.9-13 percent (7.9). Consequently in the Bangladeshi and Pakistani communities living in the UK there is a strong probability that chronic HCV infection is common and that, consequently, the prevalence rate is likely to be substantially higher than in other populations. There is evidence in support of this expectation that shows that the prevalence of Hepatitis C infection is higher in people living in the UK but originating in Pakistan than would be expected from the indigenous UK population.
1.2 Background

During the period being reported The BHA Hepatitis C Support Project and the ISB worked in partnership to deliver a series of information and awareness workshops on Hepatitis C in mosques and community settings across Greater Manchester. This principal partnership worked together with representatives of 8 mosques, the British Liver Trust and the Hepatitis C Trust to raise awareness among the South Asian community. Principal delivery was in mosques and at the annual Manchester Asian Mela. In addition to the principal organizations mentioned above the project was assisted by various voluntary sector organizations, members of the local public health department and local General Practitioners (GPs).

2. Why raise awareness?

The key determinant of the successful treatment of HCV infection is early diagnosis. Raising awareness of risk factors involved in transmission and encouraging knowledge of symptom recognitions helps with increasing the rate of early identification of those who are infected. This, in turn assists in providing an opportunity for life saving and cost effective interventions. A failure to provide such awareness campaigns using appropriately targeted information that can assist people in identifying whether or not they are at risk and to recognise symptoms can mean that these individuals are at significant risk of an early death through a missed opportunity of early diagnosis.

This project focused on recognised local ethnic minority groups living in the UK who have been identified as being the necessary focus of national and local information campaigns. A multi-centre study was conducted by Graham Foster from London to determine prevalence among migrants originating from Pakistan and Bangladesh.

3. Method of Delivery

The information sessions were delivered bilingually in Urdu, Punjabi and English by GP representatives of ISB (Islamic Society of Britain) and staff from the BHA Support Project.
The information provided was culturally appropriate to the target audience. The format of the delivery sessions was pre-determined and each session was designed to be interesting and culturally sensitive as well as being informative. The sessions were structured so that there was ample opportunity for participants to take part in discussions on relevant topics and for them to ask relevant questions. A meal was also provided during the delivery of the session; this was important to make the event social as well as medically informative.

The sessions were delivered to a total of 396 individuals from the identified communities, of which 170 were women and 226 were men. Monitoring and assessment forms were used to give the participants the opportunity to feedback their opinions on the events. Analysis of this feedback, (examples of which are available in the Appendix of this report), showed that participants found the delivery sessions to be informative and instructional. In general, the feedback was extremely positive, and reinforced the necessity of implementing this type of programme.

The implementation of the information sessions also made apparent the extent to which misinformation and stigma have impacted upon this community’s perception of the condition. A key element of combating this with the provision of clear and unambiguous information was the distribution of flyers and posters, specifically produced for the project that provide the relevant information and which were left at participating mosques to continue to disseminate the information to as many people as possible. These flyers gave clear information about Hepatitis C and included guidelines for individuals on how to request a Hepatitis C test from their GP.

At times, the sessions were delivered to separate groups of men and women with project presenters being of the appropriate sex and able to deliver the session in the appropriate languages.
3.1 Pre - Session Work

Prior to information sessions taking place there was a great deal of preparation to be completed. It was found that preparing for a mosque session took longer in reality than expected and involved successfully moving through a number of stages leading to the successful implementation of an information session. In summation, these stages were;

- Contacting and meeting with representatives of the local Primary Care Teams (PCTs) of the area to inform them about the work that was being undertaken and to discuss content and possible collaboration. This stage took much longer than was initially anticipated as it sometimes proved to be difficult to arrange meetings with the relevant people.
- Liaising with existing community networks and relevant Black and Minority Ethnic (BME) organizations
- Contacting local GPs in the area the intervention will take place
- Identifying and liaising with the key contacts for the mosque
- Continually reinforcing the liaison with the mosque to ensure that information flyers are distributed and that local people are informed in good time ahead of the planned intervention.
- Organising refreshments for the day
- Printing and collating monitoring forms
- Preparation and collation of information for participants

Resources required for the session:

- Hepatitis C Information Banners
- BHA staff including expert patients
- ISB team
- Overhead projector and laptop
- Hepatitis C Flyer and Posters
- Monitoring Toolkit
- Refreshments
3.2 The Hepatitis C Workshop

At the beginning of each presentation, participants were asked to complete a short questionnaire about Hepatitis C to judge their actual knowledge. The same questionnaire was distributed again at the end of the session and, comparison of the results, was used as an indicator of whether or not knowledge of the subject had improved as a result of the session delivery.

The main part of the session was delivered by the presenter giving information verbally and through the display of a PowerPoint presentation. The main areas of presentation were focused on knowledge of the condition, transmission, symptoms, treatment and the effects of late diagnosis and non-treatment. It was important that the visual material used was clear and easily understood by all of the participants.

The main body of each of the presentations was divided into two sections so that participants had sufficient time for group work during which they had the opportunity to consider the questions posed by the facilitators. Each of the groups was facilitated by with members of the BHA staff or the GP taking part in the session delivery. Participants were always encouraged to express their opinions, doubts, or fears about the condition.

Following the main information session and the group work portion of the session, expert patients were present at the presentations to describe their own personal experiences of contracting and treating HCV. This proved to be a very powerful and emotive way of getting the reality of the condition across to people who had the opportunity to talk to and question those who had real life experiences of the disease to share.

Where possible, South Asian women service users joined the team making the sessions more impactful through sharing their personal experiences.
At the end of each session each participant received an information pack to take away. This pack was filled with relevant and accessible information in both English and Urdu. The flyer that had been produced by BHA featured a tear-off slip which could be given to a GP to request a Hepatitis C test (Appendix 3).

It was found that implementing the presentations within and with the cooperation of the Mosques enabled us to gain access to a greater number of men; in other community setting men are generally more difficult to access than women. The sessions were advertised through flyers and through word-of-mouth, primarily managed by mosque representatives acting on behalf of the presenters and indicating the importance of the work to establish good links with them before scheduling the presentation. The sessions were delivered between prayer times, allowing the team access to the people attending the Mosque for prayer.

3.2.1 The Hepatitis C information Flyer

Through the support work and information sessions, it was clear that there was a great deal of confusion and misinformation circulating among communities with regards to Hepatitis A & B. The need to discuss these related illnesses and other conditions were acknowledged. To assist in this, information materials and banners were produced that clarified key points including transmission routes and symptoms of the three conditions. The Hepatitis C flyer contained information specific to this series of presentations and with content created specifically to be used with the Muslim community.

The cover of the flyer features the word ‘Iqra’, the Arabic term meaning ‘Read’. This is a term from the Quran which describes the importance of individuals seeking out beneficial knowledge. It is a term Muslims are generally familiar with and the significance of which would be generally recognized. This word was used as it was considered that having this Arabic term on the flyer would signify to an individual its importance giving it less chance of being ignored or thrown away. In addition the term indicates a deeper meaning relating to the importance of sharing the contents within.
The settings with the various Mosques varied according to size and management. Although, the majority of Mosques afforded ample room for both men and women to be seated in the same area, some requested that the different sexes access the presentation using separate rooms. On one occasion there was a microphone linked to speakers in different rooms meaning that the different sexes had access to the same session at the same time but in different locations. Where it was necessary, the BHA staff members were able to deliver separate sessions where requested. One aspect of this separation of the sexes was that female facilitators noticed that female groups generally felt more comfortable when asking questions in a female only environment.

Some Mosques were better equipped than others to assist in these types of presentation and were keen to support initiatives for the community. In general, the Mosques that were approached to take part were both welcoming and accommodating. The posters and flyers produced for the intervention were also left with each participating mosque to display and pass on to others attending the mosques. Future plans entail ensuring a large number of mosques are sent the poster to display for information (see appendix).

The on-site testing offered during the session held in Bolton and arranged and managed by the Bolton Public Health Department was very well received and showed how effective immediate and on site testing linked to information campaigns can be.

4. Analysis of Participant Feedback

To gauge the effectiveness of the presentations different monitoring tools were used, including pre and post intervention questionnaires and a participant feedback form. Analysis of this feedback indicated that:

- Although most people within the target group had heard of Hepatitis C prior to the presentation they were very often confused about the facts.
- In particular there was confusion about the different transmission routes of Hepatitis A, B and C and the symptoms. This was particularly related to the relationship between dirty water, food, good hygiene etc. and the transmission of the different categories of viral hepatitis.
• With the target group of the presentations there was a lack of knowledge of the risks related to contracting hepatitis C prior to the presentation being made.
• Some people felt offended that their community was being targeted for provision of this information. (Which, in fact, they were. But in a positive sense to address the known higher than average rates of infection among this population.

Common Questions asked by Participants

During the session the following were the most commonly asked questions.

• ‘Does Hepatitis A lead to B and then C?’
• ‘Can you get it at any age?’
• Can you get Hep C from toilet seats?
• Is Hep C related to bad hygiene?
• Can you catch Hep C from the air – particularly polluted air?
• Can you get it at any age?
• Can it be passed on to children?
• Can children be tested and, if yes, at what age?
• Can you get Hepatitis B and C together?
• I have heard babies in the USA can be vaccinated – why is this not happening here?
• If a person is infected in Pakistan can they be treated here?
Some representative comments made by the participants

“I went for the test. After that – all is fine. I’m really pleased ” **Female 54 Cheadle**

“I have had Hepatitis C but I didn’t want to disclose it or talk about it in the session but I do think what you are doing is excellent. Not everyone can talk about it openly but it’s so important people understand about it”. **Female 38 Longsight, Manchester**

"Don’t you think the facts are being exaggerated? Is it really that bad a situation?" **Female 45-Bolton Mosque Session**

"I was diagnosed with hepatitis c in Pakistan but heard a lot of bad stories about the treatment so I delayed it. I wish I had known all this information earlier. I went through the treatment but I don’t think I still fully understand everything about Hepatitis C. It is distressing ", **Woman 50 - Cheetham Hill Manchester.**

“I’m disappointed that I didn’t know about this before, its so important for the community to know this” **male 52 - Manchester**

**Feedback from partners and stakeholders**

“I feel that the project has been excellent in raising awareness of this preventable, curable and potentially fatal condition. My experience in the event I facilitated at the local mosque was very well received and found to be very beneficial to the people who attended, young and old. The session helped to clear myths and misconceptions regarding this condition.”

**Dr M Shahzad Amin - Khizra Mosque**
5. Conclusion

The implementation of this set of information sessions reached 396 people in the South Asian community of Manchester. In so doing it presented the facts pertaining to Hepatitis C infection and corrected commonly held myths and misinformation about the disease. It also addressed the issue of stigma that so often accompanies infectious diseases.

However, to be more effective more time and resources are required to continue to provide this kind of information session. A follow up study is also necessary to ascertain how many of those reached in the initial series of information sessions has retained the information, changed their lifestyle accordingly and / or have gone on to test to see if they are infected.

The series of presentations was successful in creating new networks and links with interested GPs and other organisations, which can only be beneficial in increasing awareness of the subject in the targeted communities.

As a pilot the series of presentations tested ways and means of designing and implementing a successful community outreach model the success of which has indicated the need to continue with this approach.
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2012 - 2013

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iv The Project Group were: E. Haque (GP, Manchester PCT, Clinical Lecturer, University of Manchester, GP with Islamic Society of Great Britain), J. Cartwright (Consultant in Health Protection, HPA), S. Fahey (Greater Manchester Hepatitis C Strategy), A Razzaq (Lead Director of Public Health for the Greater Manchester Hepatitis C Strategy and Director of Public Health for NHS Trafford), M. Prince (Hepatologist, Central Manchester University Hospitals NHS Foundation Trust), Julie Davies (Health Projects, The BHA)

v G Uddin et al, ibid
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2012 - 2013

Expert Patient at Cheadle Mosque

Mela event 2012

Working in partnership with the HEP C Trust

Expert patient volunteers
Khizra mosque session - Cheetham Hill, Manchester
Appendix I – Event Poster

Do you know about Hepatitis C?

- It is only passed through blood
- There is a simple test – ask your GP
- There is a treatment and most people can be cured
- There is no vaccine for Hepatitis C
- Do not go abroad to seek medical treatment
- Be careful when you travel abroad – think about street barbers and reusable medical equipment
Appendix II – Event Banners on Hepatitis A, B & C

Do you know about Hepatitis C?
- It is only passed through blood
- There is a simple test – ask your GP
- There is a treatment and most people can be cured
- There is no vaccine for Hepatitis C
- Do not go abroad to seek medical treatment
- Be careful when you travel abroad – think about street barbers and reusable medical equipment

Do you know about Hepatitis B?
- It can be a short or long-lasting illness
- It can be very serious
- It is spread by infected body fluids, blood, sex fluids and from mother to baby before birth
- It can be prevented by vaccination – ask your GP about it
- Get vaccinated before you travel to Middle East and Asia

Do you know about Hepatitis A?
- Is a short lasting illness
- Your skin and eyes can go yellow
- It is caused by infected hands, food and water
- It can be prevented by vaccination – ask your GP about it
- Get vaccinated before you travel to Middle East and Asia

(Qura - Koofi)
The Messenger of Allah (SAW) said:
Seeking the knowledge is incumbent on every Muslim.
(Ibn Hajar Al Asqalani, Al-Mustadhirii al-Muyad)
Appendix III – Event Flyer

Five things you should know about Hepatitis C

1. It is only passed through blood
2. There is a simple test – ask your GP
3. There is a treatment and most people can be cured
4. There is no vaccine for Hepatitis C
5. Do not go abroad to seek medical treatment

You can be careful when you travel abroad – think about street barriers and reuseable medical equipment.

Further Information

The Islamic Society of Manchester
www.ism.org.uk
email: ismmanchester@oug.com
HIV/STI Awareness Project: 07886 112058

El A ‘Hepatitis C Support Project
www.elahc.org.uk
email: annawasi@elahc.org.uk
St Hilda’s Llll: 1197 871 2772 / 07856 276956

Greater Manchester Hepatitis C Network
www.ghcapps.com
Sukhbir Talley: Programme Manager
sukth allen@nhs.net

Hep C Trust
www.hepctrust.org.uk
0300 792 00 22

British Liver Trust
email: info@britishliver.org.uk
Freephone: 0800 002 7030
General Inquery: 01222 48 1122

Do you know about Hepatitis C?
Five things you should know about Hepatitis C

- It is only passed through blood
- There is a simple test – ask your GP
- There is a treatment and most people can be cured
- There is no vaccine for Hepatitis C
- Do not go abroad to seek medical treatment
- Be careful when you travel abroad – think about street barbers and reusable medical equipment

There are also two other kinds of Hepatitis –

Hepatitis A
- It is a short lasting illness
- Your skin and eyes can go yellow
- It is caused by infected foods, food and water
- It can be prevented by vaccination – ask your GP about it
- Get vaccinated before you travel to Middle East and Asia

Hepatitis B
- It can be a short or long lasting illness
- It can be very serious
- It is spread by infected body fluids, blood, sex fluids and from mother to baby before birth
- It can be prevented by vaccination – ask your GP about it
- Get vaccinated before you travel to Middle East and Asia
Further Information

The Islamic Society of Britain
www.isb-england.org.uk
Email: isbmanchester@googlemail.com
Health Awareness Project: 07885 183919

Dia Hepatitis C Support Project
www.diahcs.org.uk
Email: shahzada@diahcs.org.uk
Shahzada Baig: 0161 674 2173 / 07568 936999

Greater Manchester Hepatitis C Strategy
www.gmmhepc.com
Siddhan Patel Programme Manager
siddhanp@manchester.nhs.uk

HepC Trust
www.hepctrust.org.uk
020 7908 0220

British Liver Trust
Email: info@britishlivertrust.org.uk
Free Helpline: 0800 955 7709
General Enquiries: 01425 481 300

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Do you know about Hepatitis C?