



THE CHALLENGE OF
HEPATITIS C
FOR THE SOUTH ASIAN COMMUNITY

a Parliamentary Roundtable Event,
supported by Bristol-Myers Squibb



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This meeting was organised by Bristol-Myers Squibb, who worked to devise the agenda, made logistical arrangements and assisted in the writing of this report.

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INTRODUCTION

ON TUESDAY 8 JULY 2014, VIRENDRA SHARMA MP CONVENED A ROUNDTABLE EVENT IN WESTMINSTER, SUPPORTED BY BRISTOL-MYERS SQUIBB, WHICH BROUGHT TOGETHER A GROUP OF EXPERTS TO DISCUSS THE CHALLENGE OF HEPATITIS C FOR THE UK'S SOUTH ASIAN COMMUNITY AND TO IDENTIFY STEPS TO IMPROVE THE DIAGNOSIS AND TREATMENT OF THIS CONDITION. ATTENDEES AT THE EVENT DISCUSSED THE REASONS WHY HEPATITIS C IS A PARTICULAR ISSUE FOR THE SOUTH ASIAN COMMUNITY AND HOW SERVICES MIGHT BEST BE DESIGNED TO IMPROVE PATIENT OUTCOMES.

Attendees at this event included representatives of NHS England and Public Health England, Parliamentarians and members of local Government, leading hepatologists and representatives from patient advocacy groups. This report outlines and builds upon these discussions and a full list of attendees is also included at the end of this document.

In order to introduce the main issues facing the South Asian community with regards to hepatitis C, attendees first heard from three speakers who outlined their experiences in this area.

- **Dr Humayun Muhammad:** consultant gastroenterologist at The Dudley Group NHS Foundation Group and member of the South Asian Health Foundation's Gastroenterology Working Group.
- **Opal Greyson:** hepatitis C specialist outreach nurse who has previously managed outreach programmes for Bedford's South Asian community.
- **Shabana Begum:** former hepatitis C patient and the South Asia Officer for The Hepatitis C Trust, the UK's largest hepatitis C specific patient group.

HEPATITIS C

HEPATITIS C IN THE SOUTH ASIAN COMMUNITY - CHALLENGES AND OPPORTUNITIES

WHAT IS HEPATITIS C?

Hepatitis C is a blood-borne virus which affects the liver. If not effectively treated, the condition can lead to serious complications such as cirrhosis, end-stage liver disease and liver cancer^{i,ii}. The condition can often be asymptomaticⁱⁱⁱ, meaning those infected will not necessarily know that they have the condition until significant damage to the liver occursⁱⁱⁱ. Typically, it takes around 30 years before an infected patient starts to display symptoms of advanced liver diseaseⁱⁱⁱ. Up to 5% of patients will die of cirrhosis and liver cancerⁱⁱⁱ, and for 50% of patients with liver cirrhosis and liver cancer, where surgery is not possible, life expectancy is just 3 months^{iv}.

Worldwide, there are approximately 150 million people infected with chronic HCV^v, with 214,000^{vi} in the UK and two of the main causes of transmission worldwide are poor infection control and injecting drug use.^v This is often a result of either contamination with infected blood or the use and sharing of infected needles amongst the IDU population^v.



HEPATITIS C IN THE SOUTH ASIAN COMMUNITY

Around 45% of the 214,000 people infected with hepatitis C in the UK have the “genotype 3” form of the infection^{vi}. According to the World Health Organization, this form of the virus is endemic in South East Asia^{vii}. For example, infection rates in certain populations in Pakistan have been shown to be as high as 25%^{viii}. According to the NHS^x, the South Asian community face transmission risks from medical or dental treatment, blood transfusions or blood products, or the use of unsterile razors and piercing equipment, in countries with high prevalence rates for this disease and with ineffective infection control measures.

Whilst general hepatitis C prevalence rates are around 0.4%^{vi} of the adult population in England, the prevalence rate amongst the South Asian community is much higher, at around 2.3%^{vi}.

“We are all seeing an increase in people from Pakistan presenting with advanced liver disease and there is a huge tsunami of hepatitis C which is about to engulf us unless we take some action.”

- PROFESSOR GRAHAM FOSTER

HEPATITIS C TREATMENT

The genotype 3 (GT-3) strand of the condition, which is most prevalent in the South Asian community, is now emerging as a difficult to treat form of hepatitis C^x. This was not always considered the case^x. Previously, research has focused on developing new antiviral agents to treat genotype 1 (GT-1) patients as they were considered to be the harder to treat population^x, but research is now increasingly turning to the development of new treatments for other genotypes, including GT-3^x. Genotype 3 patients may respond less well to interferon-based therapies than those with some other forms of the disease as this genotype is associated with higher rates of advanced fibrosis^x and cirrhosis, which can worsen tolerability to interferon^x.

Hepatitis C poses significant challenges for the NHS and Public Health England (PHE) estimate that with current levels of treatment, incidence of hepatitis C-related end stage liver disease will continue to rise in England until around 2030^{xi}. However, a number of new treatment options are emerging which have the potential to improve efficacy and significantly impact on the incidence of hepatitis C-related end-stage liver disease^{xii}. Other health economists estimated that, using current treatments, prevalence of hepatitis C could be reduced to less than 85,000 cases by 2030 (down from the current 144,000)^{xiii}. However, it is estimated that using new and more effective treatment options while increasing treatment rates to a peak of just 14% of the patient population (from the current 3%^{xii}), prevalence could be reduced to just 5,300 patients^{xii}. This is, in part, due to the increased efficacy of these treatments and also due to potentially improved adherence with well tolerated all-oral therapies which enables wider treatment coverage^{xii}. This is important for South Asian patients, for whom a lack of information about hepatitis C and the stigma associated with having a blood borne virus can often prove a barrier to being tested or receiving treatment^{xiv}.

HEPATITIS C IN THE SOUTH ASIAN COMMUNITY: THE PATIENT PERSPECTIVE



SHABANA BEGUM, SOUTH ASIA OFFICER FOR THE HEPATITIS C TRUST

I returned to Pakistan, where my family are from, several times when I was growing up. On one of these trips, as a thirteen year old I got a fever and was taken to the family doctor who gave me an injection. I don't know why they used an injection rather than tablets. I recovered and later I returned home to the UK.

More than 20 years later and now married with children of my own, I began to feel increasingly unwell. Usually gregarious and full of life, I was constantly exhausted and devoid of energy or enthusiasm for both life and work. My GP conducted a series of general tests but none of them were able to identify the root of the problem until after several visits and much persisting later, I was diagnosed with hepatitis C in early 2005. My GP had been left with just two tests left to run, HIV and hepatitis C. They had incorrectly assumed that coming from a South Asian background I would object to being tested.

After being diagnosed I was really upset. I instantly thought my life was going to come to an end. Also I did experience a lot of stigma from my community, but I never hid the fact that I had the virus. I found out that I wasn't the first in my family to have contracted hepatitis C and several close relatives had even died from the condition.

I was lucky to be offered treatment soon after my diagnosis and within months had begun a six month course of pegylated interferon daily pills and weekly injections. This course of treatment was very difficult and I suffered side effects including ulcers, weight and hair loss and general aches and pains. Despite this, in November 2005, it was finally confirmed that treatment had been successful and I was clear of the virus.

I now work to raise awareness of hepatitis C in South Asian communities. I was asked to do this by my hep c nurse who told me how important it is to have people in the South Asian community championing treatment and testing for this disease so we can overcome the fear and stigma associated with it. I now work with the Hepatitis C Trust to raise awareness of the virus and I have worked on very successful national campaigns such as the 'face it' campaign for the Department of Health.

Nine years after clearing the virus, I attend Asian festivals and mosques with The Hepatitis C Trust's Testing Van as well as working on numerous national awareness campaign and projects to reach out to all kinds of minority, at risk groups of people.

It is vital that everyone is aware of this virus, regardless of their ethnicity. We find that people don't talk openly about hepatitis C because there is a lot of stigma surrounding hepatitis, especially in the South Asian community. But alongside my colleagues at the Hepatitis C Trust, I make every effort to overcome this barrier through information and education.



HEPATITIS C IN THE SOUTH ASIAN COMMUNITY – BARRIERS TO DIAGNOSIS AND TREATMENT

Whilst organisations such as Public Health England and NHS Choices have made some progress through awareness raising campaigns such as 'Hepatitis C: The more you know, the better'^{viii}, there is still much that needs to be done. There remain a number of barriers which prevent the South Asian community from being tested, diagnosed and treated for hepatitis C. Attendees highlighted that many of these barriers are the result of social stigma. For example, many women are unwilling to be treated for hepatitis C as it involves multiple trips to a doctor and many injections. It is often feared that this will make it difficult for the female patient to find a husband, a major cultural sensitivity amongst this community. On the other hand, attendees also highlighted other attitudinal factors, such as a degree of apathy about the need to receive treatment amongst South Asian males, compounded by the asymptomatic nature

of the condition. According to attendees, this stigma often arises from misunderstandings around the nature of hepatitis C and how it is contracted, with many believing it to be a sexually transmitted disease. This may be associated with current, intravenous, treatment options being delivered via sexual health clinics and similar facilities. With new treatment options also having the potential to be delivered orally, rather than requiring injections, it may be possible to alleviate these fears.

“The most important barriers [to hepatitis C treatment] in [South Asian] males are attitudes. Many think ‘Why should I test myself? I’m not bothered’.”
- DR HUMAYUN MUHAMMAD

HEPATITIS C

DURING THE ROUNDTABLE DISCUSSION, ATTENDEES IDENTIFIED A NUMBER OF PROBLEMS WITH THE WAY IN WHICH SERVICES ARE CURRENTLY DESIGNED:

- **INAPPROPRIATE CARE SETTINGS:** Currently, hepatitis C services are provided by a range of providers including Terrence Higgins Trust facilities, drug outreach centres and sexual health clinics. Whilst such settings may prove appropriate for patients infected as a result of injecting drug use, they often prove counterproductive for the South Asian community. The stigma associated with being treated in such centres often prevents patients from coming forward for diagnosis and treatment and reinforces negative community perceptions surrounding hepatitis C.
- **AWARENESS AMONGST GPs:** attendees agreed that GPs have insufficient knowledge about Hepatitis C and do not understand the cultural sensitivities relating to the South Asian community. There is also anecdotal evidence to suggest that GPs are unaware of the potential to cure hepatitis C using new and effective treatments. This has led to insufficient number of referrals, with fewer people coming forward for treatment.
- **LANGUAGE BARRIERS:** Currently, there is a lack of information available in the languages spoken by the South Asian community, such as Urdu or Punjabi.
- **LACK OF LOCAL PRIORITIZATION:** It was highlighted that some local commissioners had rejected proposals from patient groups to introduce awareness raising and testing campaigns as they did not have the funding or capacity to treat an increased number of newly diagnosed patients. Attendees identified how, in the long term, this approach costs the NHS money as patients with advanced hepatitis C will require more expensive treatments such as liver transplants
- **FUNDING CONCERNS:** The Hepatitis C Information Line, a telephone advice service for the South Asian community introduced as part of the NHS Choices “The More You Know The Better” campaign is no longer operational as the project has come to an end. A consensus emerged that funding was a problem across a range of different projects. There are also concerns that CCGs will not have sufficient funding to allow for immediate access to new treatments when they become available, delaying improvements in care.
- **GEOGRAPHICAL VARIATION:** It was suggested that services and awareness raising campaigns are more effective in some localities than others. For example, anecdotal evidence suggests that the South Asian community is much more aware of issues surrounding hepatitis C in London than in other areas.
- **IMMIGRATION POLICY:** Some attendees expressed concerns around the design of immigration services and their impact on access to healthcare. It was feared that, if new immigrants to the UK from the South Asian community felt unable to approach a GP, then a number of hepatitis C cases would remain undiagnosed and untreated.



HOW CAN SERVICES BE REDESIGNED?

Having identified the problems with existing service provision, attendees discussed what best practice would look like, and made a number of recommendations as to how existing services could be better organised:

- **UNDERSTANDING CULTURAL SENSITIVITIES:** As noted above, many hepatitis C services are provided in settings such as sexual health clinics and Terrence 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:** Attendees identified that education, diagnosis and treatment would be best delivered if it was 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 important role in helping to reduce the stigma associated with hepatitis C. There are a number of examples of where this approach has been successful, including work by the British Liver Trust in Bolton, the BHA in Manchester and by Opal Greyson in Bedford (see case study box below).

- **COMMUNITY CHAMPIONS:** Awareness of hepatitis C is one of the major barriers preventing South Asian patients from accessing treatment. It was therefore suggested that a series of "Community Champions" should be created. 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.

- **IMPROVED RESEARCH:** As the South Asian Health Foundation has noted, there has been relatively little research into the scale and impact of hepatitis C in the South Asian community. A greater base of research would allow for more accurate epidemiology of this condition and would give a better indication of where service improvements should be prioritized.
- **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.



CASE STUDY: OPAL GREYSON

WHAT DOES EFFECTIVE REDESIGN LOOK LIKE?

Opal Greyson is a hepatitis C specialist outreach nurse, currently working in Bedford and Luton. She has previously instigated and managed a number of outreach projects to raise awareness of hepatitis C in the South Asian community and to increase the number of patients being diagnosed and treated.

Opal Greyson's career as a hepatitis specialist nurse began in London, where she was involved with a number of successful projects with the South Asian community. However when she moved to Bedford, she was shocked to find that she only had four patients drawn from that community. With a large South Asian population in the area, Opal expected to have between 114 and 135 patients. She identified that the reasons behind this were that Department of Health awareness campaigns, which had been successful in London, had not filtered down to Bedford. Similarly, all local disease specialism was geared towards injecting drug use and had not considered the specific cultural sensitivities associated with the South Asian community.

To rectify this, Opal looked to redesign existing services in order to improve awareness, treatment and care in her community. Firstly, she looked to address poor levels of awareness in GPs, holding education evenings at GP surgeries, about the needs and challenges associated with hepatitis C. This event was considered to be a success and a number of GPs pledged to offer clinic space to help support drives to improve treatment and diagnosis for the South Asian population. Secondly, realising the importance of "going where the patient is" to improve outcomes, Opal engaged the community directly and won the support of local religious leaders. She conducted a morning clinic at one local gurdwara and mosques raising awareness of the condition and giving out testing kits. This system was a great success and she often found that patient demand would outstrip supply of testing kits.

Overall, Opal found that her outreach project had a positive impact on hepatitis C care in Bedford. Following this programme, 82 people came forward for testing, 74 completed the test and an extra three patients were successfully treated. As well as improving patient outcomes, this has proved to be cost effective. This is due to the prevention of advanced liver disease and associated treatment and management costs, as well as services being used more efficiently.



CONCLUSION

Hepatitis C prevalence in the South Asian community is higher than in the general UK population and it is critical that steps are taken to better diagnose and treat these patients. To do so, attendees identified how service design must reflect the needs and concerns of the patient population. For instance, whilst injecting drug users may find the delivery of services through sexual health clinics or drug outreach centres to be appropriate, for South Asian patients this approach can actually prove counterproductive. This is due to the stigma surrounding blood borne viruses in the South Asian community and to address this, it is important to engage religious and cultural centres within the delivery of services. Through these groups, awareness raising sessions can be arranged, community champions recruited and practical advice on treatment and the implications of the condition developed. This can help to break down the current stigma surrounding hepatitis C and help patients to feel comfortable about coming forward with their condition and discussing its implications.

Recently released and emerging treatments have the potential to transform outcomes for the South Asian population and it is important that patients are able to maximize the benefit of these drugs. Not only do these new treatments have a much higher potential to cure the disease in individuals and hence reduce transmission rates, they include previously unavailable all-oral regimes, with a reduced side effect profile and in some cases a shorter duration of treatment. To ensure that these benefits are felt, it is important that services are designed to reflect the needs of the South Asian community.

ATTENDEES

- Virendra Sharma MP (Chair) – Member of Parliament for Ealing Broadway and Vice-Chair of the All-Party Hepatology Group
 - Nik Barstow - Director of Engagement & Involvement, BHA
 - Shabana Begum – South Asia officer, The Hepatitis C Trust
 - Neil Cowan – Policy and Public Affairs Adviser – Hepatitis C Trust
 - Professor Graham Foster - Professor of Hepatology at the Blizard Institute of Cell and Molecular Science, Queen Mary University London
 - Opal Greyson – Hepatitis Specialist Nurse, Bedford Hospital
 - Richard Hall – Co-founder, Liver4Life
 - Andrew Jones – Bristol-Myers Squibb
 - Alison Keating – Head of Drugs and Alcohol (London), Public Health England
 - Dr Humayun Muhammad – South Asian Health Foundation Gastroenterology Working Group
 - Stephen Pound MP – Member of Parliament for Ealing North and member of the All Party Group for India
 - Yasmin Qureshi MP – Member of Parliament for Bolton South East and member of the All Party Group for Pakistan
 - Ranjit Senghera –Senior Manager for Equalities and Health Inequalities – Inclusion Health, NHS England
 - Jim Shannon MP – Member of Parliament for Strangford
 - Cllr Hitesh Tailor – Cabinet Member for Health, Ealing Council
 - Dimitar Tonev – Disease Area Head (Virology) , Bristol Myers Squibb
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