

From policy to practice: Exploring the burden of Hepatitis B & C in the UK Nepali community, and the barriers to community migrant testing

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Study Abstract:

Context: The UK Nepali community is a unique migrant population, with recent expansion and presence in the UK following the approval of settlement rights to Gurkha veterans and their dependents granted from 2004 to 2008. The community is heterogeneous in relation to caste and religion, with Gurkha military ties the principal denominator to bind this newly arrived population. Many in the community have settled close to military institutions, with a new migrant population that has emerged as a result around the Aldershot area in Hampshire and Surrey.

The health awareness and needs of the UK Nepali community is poorly understood, including in chronic viral hepatitis (CVH), with increased hepatitis B and C (HBV and HCV) risks that are well described in migrant groups from the neighbouring countries of India and China, but with no previous studies in the UK Nepali population.

HBV and HCV is a global disease, and carries a higher death toll than that seen in comparison to HIV or tuberculosis. CVH disproportionately affects some migrant groups, with case-finding to test at-risk groups part of national guidance by the National Institute of Health and Care Excellence (NICE), as well as the World Health Organisation (WHO), with WHO goals that look to eradicate HBV and HCV by 2030.

At the same time, migrant groups such as the recently arrived Nepali community face growing political and social pressures, with rising nationalism and anti-migrant sentiment seen across Europe, and with blood borne virus rates that have been specifically targeted by right-wing political groups in the UK.

CVH is typically asymptomatic until advanced and severe complications develop; but with highly effective and well-tolerated treatments available if disease is identified at the right time. Effective case-finding to identify CVH in at-risk groups is therefore a priority, and a key aim of national (NICE) CVH testing guidance. The awareness and implementation of this policy is however largely unknown, with particular deficits in our understanding of testing activity in primary care, which remains crucial to delivering CVH testing in migrant communities nationally.

The following study therefore presents a comprehensive exploration of the potential barriers and facilitators that exist towards CVH testing in migrant groups, taking the Nepali community as the focus of this thesis. It explores the factors that exist at the policy level towards effective testing delivery in migrant groups, and at the local (community) level towards CVH testing in primary care, and compares the understanding and perception of the newly arrived Nepali community towards liver disease, and the development of a community based study to identify the CVH risks in the local Nepali population.

Intervention: At the macro-level a policy prioritisation framework was utilised to look at the factors that influence how CVH testing policy can achieve political attention and resources for its implementation. At the community (micro) level, focus group studies were undertaken with members of the Nepali population to explore the awareness, knowledge and perception of liver disease, as well as the potential risks and barriers that may exist towards health engagement strategies. Qualitative focus studies were also conducted with General Practitioners (GPs) from 3 local GP practices who serve the recently arrived Nepali community, to understand the awareness, knowledge and perception of CVH testing in migrant groups. A dedicated community-based testing intervention was then developed to directly assess HBV and HCV prevalence in the local Nepali community, building on the findings from local focus group studies.

Outcome: At the policy level, the National Institute for Health and Care Excellence has produced CVH testing recommendations that are far-reaching, and would have a positive impact on CVH testing in migrant communities, including the UK Nepali population. However, policy has been developed in a top-down approach, without clear leadership to coordinate testing activity, and without community level cohesion that is evident at the Local Authority, local health service (currently Clinical Commissioning Groups (CCG)) or primary care level.

At the micro-level, focus group studies in the Nepali community identified high-levels of awareness of liver disease, and although understood principally as “jaundice”, liver disease is viewed as a disease to be feared. Whilst perceptions of stigma are evident, with associations to extrinsic agents such as Spirits and Witch Doctors in disease and cure, there is an overwhelming desire to engage with modern healthcare approaches in the UK, with primary care a trusted and well sought counsel to learn about liver disease. Focus group studies in primary care though suggest significant barriers to CVH testing in migrant groups, with low levels of awareness and knowledge towards existing policy, and with active perceptions of prejudice and harm if they were to engage in CVH testing activity in migrant communities.

As part of a dedicated testing study, HBV and HCV testing was undertaken in 1005 participants (984 unique individuals) from the local Nepali population, with the close and integral involvement of a specially developed Nepali research committee. DBS (Dry-blood spot) testing was used to deliver testing at centrally located community sites. Significant anti-migrant sentiment was expressed during the study, limiting the ability for formal study advertising through written or visual media. Despite this, we were able to recruit close to 1000 members of the local community, with word-of-mouth a powerful route to disseminate testing information in the Nepali community. Absolute rates of active CVH were low, with HBsAg detected in just 3 (0.3%) of individuals and HCV Ab detected in 4 individuals

(0.4%), although none of these participants had detectable RNA levels on subsequent testing. Evidence of previous HBV exposure was however raised, with 9.25% (91) of participants demonstrating HBcAb positivity. Associated risk factors for HBcAb positivity were lower educational status and male gender.

Conclusion: Overall, the absolute rates of active CVH appear low in Nepali community, but with higher rates of previous hepatitis B exposure that warrant the need to understand disease risks in the wider Nepali community. At the policy level, there are gaps in the effectiveness of policy across the policy prioritisation framework, with a lack of leadership and direction to facilitate testing at the community level. Members of the Nepali community view CVH as a disease to be feared, and whilst stigma arises as a perception towards liver disease, the overwhelming emphasis is a wish to engage with health care professionals, with good levels of engagement demonstrated in our subsequent community-based testing studies. The perceptions raised in primary care though demonstrate a reluctance to engage in CVH testing activity in migrant groups, with the need for further interventions to modify testing behaviour if we are to reach global and national CVH eradication goals.

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My supervisors have been pivotal in providing advice, support and direction, as well as mentorship in my research and career development. Professor Aftab Ala has provided vision and support, and continues to act a mentor in my consultant career. Professor Jane Hendy was my principal supervisor in the early part of my research work, prior to her move to Brunel, and was instrumental in helping me focus my objectives, and in developing my framework. Professor Simon de Lusignan has acted as my supervisor throughout my thesis work, providing invaluable direction, and Martyn Whyte has provided support since Jane's departure from the department.

My thesis takes a broad and holistic approach to look at the potential barriers and facilitators that effect migrant CVH testing, and the list of those who have supported me along this process is too long to mention here, but is not without gratitude.

The Nepali community are the focus of my thesis, and members of the local community have been wonderful in the way they welcomed and supported my work. In approaching a new community, we worked initially with a handful of community leaders, blossoming into a network of community advocates, including local council leaders who were instrumental in the focus group and testing work in this thesis. We had broad ambitions in testing up to 1000 members of the community, and achieving this target is the result of the hard work of a dedicated group of research collaborators from the University of Surrey and Frimley Park hospital, including Mihaela Petrova, local council leaders, and most importantly, the peer-advocates from the local Nepali community, who acted as dedicated research group to help direct and promote our testing work. Ramji Tiwari deserves special mention as an honorary member of our research group, in facilitating community links, and with important roles in translation.

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Contributors:

This thesis explores potential barriers to CVH testing in migrant groups and the Nepali population from the macro, policy-level to the micro, community-level, involving qualitative and quantitative study. Given the scope and extent of this work, it has been conducted with input and direction from my (academic) supervisory team, as well as a significant number of researchers and peer-advocates in the Nepali community.

The following section details the roles and responsibilities of the key members involved during this work, detailed in order of the chapter structure of this thesis.

Political, Social and Health aspects of migration and the UK Nepali community- SM

Policy Analysis: context - SM

Policy Prioritisation Framework analysis – SM

Focus Group study in the Nepali community:

- Focus Group Guides – JH
- Moderators – (Nepali volunteers, JH involved in training)
- Audio transcription and translation – RT

Thematic Analysis:

- Transcript Coding – SM
- Higher order themes – SM JH

Primary Care Focus Group Study:

- Focus Group Guide – SM JH
- Moderator - SM
- Audio transcription – SM

Thematic Analysis:

- Transcript Coding – SM
- Higher order themes – SM JH SL

Nepali Community CVH Testing Study:

Testing Activity – SM MP AA RT FPH Research Nurses, Nepali Community Advocates

Data analysis – SM (input from Clinical Informatics Group, University of Surrey)

Discussion

Implications, Comparisons in Literature, Limitations – SM

SM Sanju Mathew

JH Jane Hendy (Professor)

RT Ramji Tiwari

SL Simon de Lusignan (Professor)

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Training Courses:

- Good Clinical Practice: August 2013, August 2015
- Welcome to your PhD: April 2014
- The PhD Confirmation Process – March 2015
- Fundamentals of Management Research Methods - Sept-Dec 2014
- Through these courses, particularly in the Fundamentals of Management Research Methods I have gained a fascinating insight into the research development process and the philosophical approaches that guide much research activity. I have used information gained through this process in my application towards focus group studies, and in developing semi-structured interviews, as well as in formatting proposals for ethics submission.
- SWiSS (Surrey Winter Statistical School) – Jan 2014 (An update of statistical research methodology, and the use of specific statistical methods in research design)
- EASL (European Association for the Study of the Liver) – April 2014 (Postgraduate course, and breaking research developments in the identification of HBV and HCV and new therapeutic strategies)
- AASLD (American Association for the Study of Liver Disease)/EASL special conference – Sept 2014 (research work accepted for presentation; practice update on case-finding and treatment strategies for HCV)

Research Group Seminars:

- Surrey Postgraduate (PGR) conference – Jan 2014 (Presented poster of research work)
- Surrey Clinical Academic Group (CAG) – regular scheduled meetings
- Guildford and Waverley CCG Research Forum – attended to present research work

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From policy to practice: Hepatitis B & C risks in the UK Nepali community, and the barriers to migrant testing across the health system

Introduction:

This thesis takes a view across the macro and micro levels to explore the potential barriers and facilitators that exist towards chronic viral hepatitis (CVH) testing in migrant communities, focusing on the UK Nepali population; a new and unique migrant community. It explores the levers that exist for action at the national policy level, and the community (primary care) level, and develops a comprehensive strategy through a mixed-methods approach to understand and directly assess CVH risks in the newly arrived Nepali community.

Chronic viral hepatitis (CVH) due to hepatitis B and C (HBV and HCV) are blood borne viral infections that affect the liver, and are the leading cause of cirrhosis (end-stage scarring) and hepatocellular carcinoma (HCC, primary liver cancer) worldwide. The global death toll seen due to CVH is rising, and is higher than that reported with HIV, and comparable to that seen for tuberculosis; with CVH the only one of these conditions with a mortality rate that continues to rise [WHO 2017, WHO May 2016].

The baseline prevalence of CVH is low in the UK, but liver disease is the 5th biggest killer, with CVH being among the leading causes for this excess mortality [CMO 2012]. There is marked geographic variation in the prevalence of CVH, with a disproportionate burden of disease that is seen in many parts of the world [Hahne SJ 2013]. Globally, only around 9% (22 millions) of all HBV patients, and 22% (14 millions) of HCV patients are estimated to have been diagnosed and aware of their disease state, and even by 2015, only around 8% of these HBV patients and 7.4% of HCV patients had received or commenced treatment [WHO Global Hepatitis Report 2017].

HBV and HCV can be transmitted from person to person, with blood borne exposure the principal route. Risk factors for acquisition include iatrogenic exposure and risk activities, such as injecting drug use, as well as mother-to-child (vertical) transmission, or infection in the first few years of life, with these vertical and childhood risks accountable for the endemicity of HBV worldwide [WHO July 2017].

Not all patients infected with HBV and HCV will develop chronic (long-term) infection, and there is variation in this chronicity based on the age at acquisition [Hyams KC 1995]. Importantly though, both acute and chronic infection may cause few symptoms, and infection therefore goes unrecognised by patient and clinician alike until end-stage complications develop (70% of adults and 90% of children may not develop symptoms of acute hepatitis B infection [Foundation for Liver Research 2004]). Testing is therefore the only way to identify infection, with effective and accurate testing strategies that are available.

Training and working as a NHS specialty doctor in hepatology, I have seen many patients who present with the complications of CVH through delayed diagnosis, with disease that was not identified or treated earlier. These patients have often developed many of the advanced complications of liver disease and portal hypertension (figure 1), with significant morbidity and mortality risks, and with the drastic interventions of liver transplantation that may be their only treatment option.

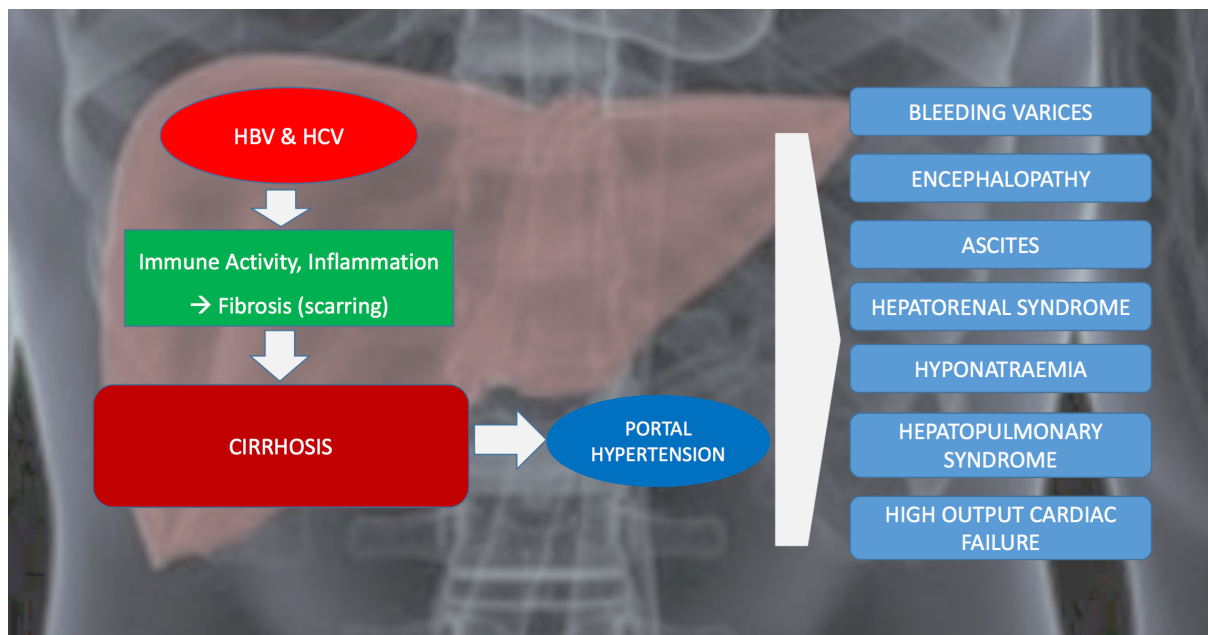


Figure 1: Summary of complications seen in end-stage liver disease (cirrhosis) (Dooley J, 12 edition), with factors that can individually or cumulatively increase morbidity and mortality in effected individuals

The tragedy in these individual cases and in undiagnosed infection is that early identification facilitates treatment to prevent liver disease progression and the development of these systemic complications. Testing is straightforward and can be delivered by a blood or saliva tests, which will identify current infection and previous exposure. Highly effective treatment now exists for viral hepatitis, and huge scientific advances have been made over the last few years to revolutionise the treatment of Hepatitis C, such that treatment for HBV and HCV is now close to 100% effective in preventing disease progression if it can be identified at the right time, and with globally driven initiatives in place to eliminate CVH by 2030 [Lawitz E 2015, Sulkowski M 2014, EASL recommendations 2015, Williams R 2014, WHO May 2016].

CVH has a global distribution, with HBV endemic in some parts of the world [WHO May 2016, WHO July 2017]. Migrant groups in the UK are thought to be at increased risks of CVH, with up to 95% of newly identified chronic HBV cases that are seen in migrant individuals [NICE 2012], and with higher

rates of HCV reported in the sentinel surveillance programmes undertaken by Public Health England, with prevalence rates between 2 to 6% in some communities, in comparison to baseline prevalence estimates of 0.4% in the UK community [PHE 2013, PHE 2017].

CVH testing in migrant communities is therefore supported in national and international guidance, with case-finding objectives to identify and engage with at-risk groups for treatment (figure 2). In the UK, the National Institute of Health and Care Excellence (NICE) released updated guidance in 2012 recommending CVH testing in at-risk groups, with specific focus on migrant communities (figure 3).

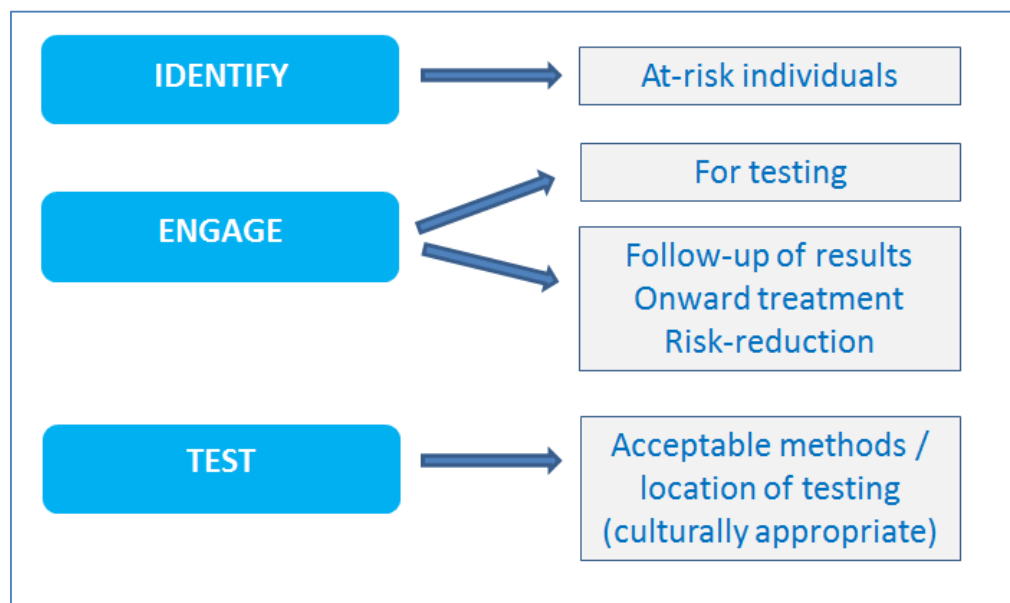


Figure 2: case-finding process in at-risk groups

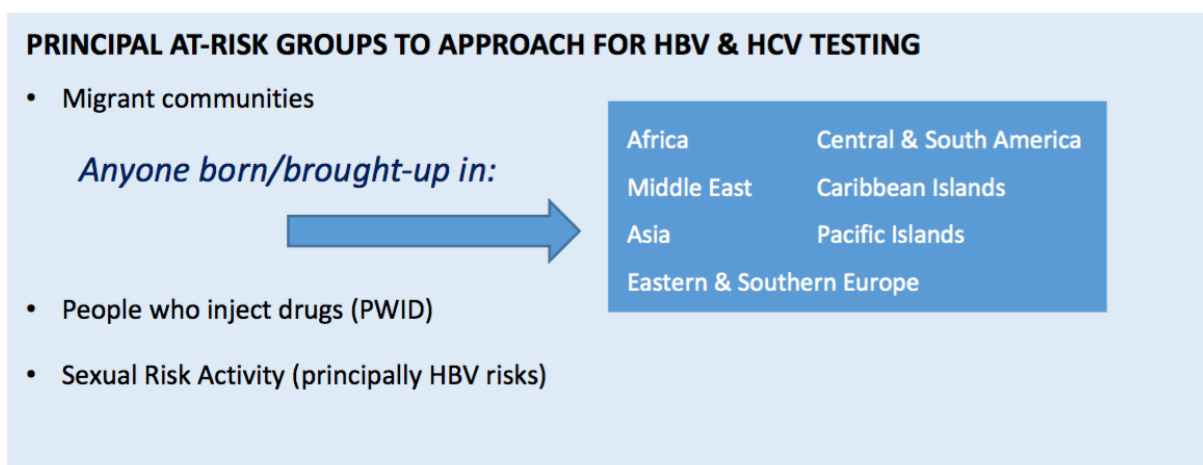


Figure 3: Principal at-risk groups to approach and offer HBV and HCV testing in England [NICE 2012]

Migrant groups do however face inequalities in healthcare access in the host country, as well as altered patterns of healthcare engagement that can leave this community vulnerable [WHO 2010], in addition to a higher burden of disease risk that may exist from their native environment. First generation migrants, and new migrant communities may be at even greater need with regard to (an unknown) disease burden [Uddin G 2010], as well as uncertainties in how to reach-out to this new community for health engagement.

The UK Nepali community is a unique migrant population in need of study, with a rapid and significant rise in population numbers following the widely celebrated approval of UK settlement rights to ex-Gurkha servicemen and their dependents in 2004 and 2009 [Home Office 2017]. This new community has settled close to established military links, with a large population that has based itself around the Aldershot garrison in Surrey and Hampshire. Indeed, estimates suggest that the Rushmoor district now has the largest population of Nepali in the UK, with an estimated 6-10% of the local population who are now Nepalese [CNSUK 2013, Telegraph February 2011].

The health needs of the newly arrived Nepali community is unknown, including in the context of CVH, with a higher burden of CVH that is well documented in the neighbouring countries of India and China [Sharma S 2015], and a unique geographic population extraction (in view of Gurkha recruitment practices) that new resides in the UK.

The Need for Study – exploring CVH risks in the newly arrived Nepali community:

Little is known about the CVH risks in the newly arrived Nepali community, or the health awareness and perception in this population. Many in the community are likely to be older, given the extension of settlement rights in 2009 to allow older ex-servicemen and their dependents to settle; with undiagnosed CVH in these individuals that may be at a more advanced stage.

There is heterogeneity in documented CVH rates within and between migrant groups, with difficulties therefore in understanding and extrapolating HBV and HCV risks amongst diverse population groups. CVH risks may also be higher in recently arrived migrants [Uddin G 2010], with the need therefore to explore chronic hepatitis B and C (CVH) risks in the newly arrived UK Nepali community.

There is a higher CVH burden suggested in members of the UK South Asian community, identified through PHE (Public Health England) sentinel surveillance data and community-based research studies [PHE 2017, Uddin G 2010, Sharma S 2015, Vedio A 2013]. Hepatitis B prevalence is estimated to be around 2% in the South East Asian region overall [WHO July 2018], with reported HCV rates in the UK South Asian population of 2.7% [Sharma S 2015], although more recent studies suggest that the prevalence rates of CVH (HBV and HCV) may be somewhat lower at 2% (1.1% HBV, 0.9% HCV)

[Flanagan S et al. 2019]. Initial case-finding initiatives in migrant groups were conducted with an estimated threshold of 2% prevalence for CVH in these groups, with cost-effectiveness analysis based on these risk-estimates, as detailed in initial NICE (National Institute of Health and Care Excellence) CVH testing guidance [NICE 2012]. The heterogeneity amongst published studies suggests firstly that this threshold may still exist, but even with the lower estimates of CVH prevalence from the latest HepFree study in the UK, the cost-effectiveness of testing migrant groups is still met at an estimated £8540 per QALY [Flanagan S et al. 2019], with growing cost-effectiveness support for migrant case-finding initiatives in other European countries, with cost-effectiveness demonstrated even at estimated seroprevalence rates of 0.41% for HBsAg and HCV RNA at 0.22% in the Netherlands [Suijkerbuijk AWM 2018].

CVH testing in migrant communities is recommended as part of national policy, with updated CVH testing recommendations issued by NICE in 2012 [NICE 2012]. National policy has an important role in coordinating and delivering testing through (existing) health facility-based testing, with primary care the principal agent tasked to deliver testing to a wide and heterogeneous migrant population, and to facilitate linkage to health services [WHO May 2016]. The awareness and uptake of current CVH testing policy is however largely unknown, with policy endeavours over the past 10-14 years that produced low levels of awareness and confidence in managing CVH, particularly in primary care [NICE 2012, DH 2004, DH 2009, De Souza 2005, RCGP 2007, APPHG 2011].

The awareness of policy, as well as the practice and perception of testing in primary care is therefore important in understanding the potential barriers that exist at the micro-level towards testing in the newly arrived Nepali population, as well as migrant testing more broadly across the health system.

At the same time, it is important to have a direct assessment of the CVH risks that exist in the local Nepali population, with uncertainties that exist in the awareness, knowledge and perception of disease in the newly arrived community, and how these sensitivities may affect health engagement practices [Norredam M 2010, Kessing L 2013].

Research Aims and Objectives:

The aim of this thesis is therefore to explore the chronic hepatitis B and C (CVH) risks that exist in the UK Nepali community, as well as the potential barriers and facilitators that exist at the (macro) policy level towards CVH testing in migrant communities, and at the primary care (micro) level towards CVH testing in migrant groups.

The objectives of the thesis are as follows:

1. To explore the political, social and health pressures faced by migrants, and the newly arrived Nepali community; and the implications of these determinants on health engagement.
2. To explore NICE CVH testing guidance as part of a (macro-level) policy analysis to understand the potential barriers and facilitators that exist in policy prioritisation.
3. To identify the potential barriers and facilitators at the (micro) primary care level towards CVH testing in migrant groups, and the recently arrived Nepali community.
4. To explore the awareness, knowledge and perception of CVH in the Nepali community, and beliefs or practices that may influence the development and uptake of health engagement strategies.
5. To develop a community-based testing intervention with members of the local Nepali community to establish CVH risks through direct study.
6. To develop an overarching analysis of the gaps that exist at the policy (macro) level and at the primary care (micro) level towards CVH testing in migrant groups, and to utilise findings from the Nepali community to explore how CVH testing delivery can be delivered and prioritised to this community, and other migrant groups.

The thesis aims to contribute an understanding firstly of CVH risks in the Nepali community, and in the development of a community-based engagement strategy; and at a higher level looks to understand the barriers that exist in testing in migrant groups at the macro and micro levels; focusing on deficits that exist at the policy level, and in primary care, with direct impact that these factors will have on CVH testing in the newly arrived Nepali community, as well as migrant groups nationally.

Structure of thesis:

The chapters in this dissertation are organised as follows:

Chapter 1 looks at the political, social and health determinants that affect migrant groups, and challenges particular to the newly arrived Nepali community in the UK. Health in migrant communities, and the potential burden of undiagnosed CVH is explored, as well as the broader inequalities that exist in health access and engagement in migrant communities.

Chapter 2 presents the research objectives of the study, and the research methodology and design, including the philosophy and theoretical framework utilised. An overview of the mixed-methods

approach used to achieve my research objectives is presented; with the findings of the study presented in chapters 3 to 6

Chapter 3 explores the findings of policy level analysis using the National Institute of Health and Care Excellence (NICE) public health guideline: “Hepatitis B and C testing: people at risk of infection”. The history and context of CVH testing policy is explored on an international and national basis, with a Policy Prioritisation framework selected to explore the gaps that exist in CVH testing policy reaching the agenda for adoption and successful implementation for migrant testing.

Chapter 4 presents the findings of a qualitative study exploring the awareness, knowledge and perception towards liver disease and CVH in the Nepali community. Focus Group study results across 4 groups in the local Nepali community are presented using a thematic analysis approach.

Chapter 5 presents the findings of qualitative studies in primary care, exploring the awareness, understanding (knowledge) and perception towards CVH testing in migrant groups in General Practitioners (GPs), with comparisons that are applied to the qualitative findings from studies in the Nepali community who are served by these practitioners.

Chapter 6 explores and presents the findings of a testing programme designed to establish CVH risks in the local Nepali community.

The Discussion and Conclusions of my study are presented in Chapter 7, with inclusion of the key findings of the study, and the potential gaps that are found from policy to practice at the primary care level in CVH testing in migrant communities, as well as potential levers for action in future interventions.

Chapter Summary:

The current chapter presents an introduction into the aims of this thesis, to identify the burden placed by CVH in migrant communities, and the uncertainties that exist in CVH risks in the newly arrived Nepali community. The principal research aims of the study, as well as an overview of the structure of the thesis is presented.

Chapter 1

The political, social and health context of migration, and implications for CVH testing engagement

Chapter 1: Migration: Political, Social and Health aspects

Abstract:

This chapter explores the pressures faced by migrant communities, and the potential impact on health access and engagement. It explores the political and social context of migration to the UK, and the political and social determinants of migrant health. The global burden of CVH is explored: the risks that are poorly defined, and disease may be undiagnosed in migrant communities. The specific political and social determinants affecting the newly arrived Nepali community are described, with the potential impact on health engagement, and the need for study to assess their CVH risks.

Migration, with the flow of people within and between countries and continents is an integral part of human society. Migration can produce economic, cultural and socio-political change, but also stigmatisation, conflict and vulnerabilities. Migrants include those individuals who have left their home country to seek a life in another country, and may be short or long term residents in the host nation.

There is frequently overlap in how migrants are defined in literature [WHO 2010], but for the purposes of this thesis the term “migrant” is used to reference those individuals born outside the UK, with “new migrants” used to reference those individuals who are recently arrived, referencing the Nepali community, who form the focus of this study [Wagner KS 2013].

Migration patterns fluctuate in time and place, but the past few years have seen a dramatic increase in the number of individuals displaced by war, conflict or persecution, with close to 60 million individuals affected worldwide. During 2014, an average of 42,500 persons per day were forced to leave their homes due to conflict, seeking protection elsewhere within their country or abroad. The resulting refugee crisis of this and previous conflicts is substantial, with close to 20 million refugees worldwide, and with the ongoing Syrian conflict now the largest contributor of this refugee crisis. Developing countries are hosting more of these refugees than ever before, but the pressures of migration on the EU from these conflicts as well as existing migrant communities are substantial, with no anticipated easing in the complex migration trends in sight [UNHCR 2015, Eurostat 2015].

The UK is the end-destination point for many of those displaced and seeking new opportunities, with the Calais Jungle a manifestation of the pressures and plight of migration and migrants [Eurostat news release, March 2015, Guardian, Taylor M 2015]. Immigration rates to the UK have doubled since the 1990's, and England and Wales have a higher proportion of foreign-born residents in comparison to similar sized European countries, including France and Germany. Citizenship acquisition is among the

highest in the UK compared to other EU states, and foreign born individuals make up close to 13% of the population, with the majority of individuals (8.1%) born outside the EU [Eurostat news release March 2015]. Census data from 2011 in England and Wales shows that there has been an increase in minority ethnic groups, whilst those defined as “White British” has declined over the same period [ONS 2011].

Migration rates to England and Wales have risen sharply since 2001, driven principally by the expansion of the EU to include Central Eastern European countries in 2004. India, Poland and Pakistan are the three most common countries of origin for those born abroad, with an 897% increase in the recorded Polish population between 2001 and 2011, which is likely to have contributed to the 46% of non-UK born respondents who identified themselves as White in the 2011 census [ONS 2012]. Cumulatively though, members of the South Asian community (India, Pakistan and Bangladesh) continue to be one of the predominant migrant communities to the UK, which is in keeping with previous census reports and trends over the past few decades [ONS 2012] (figure 3).

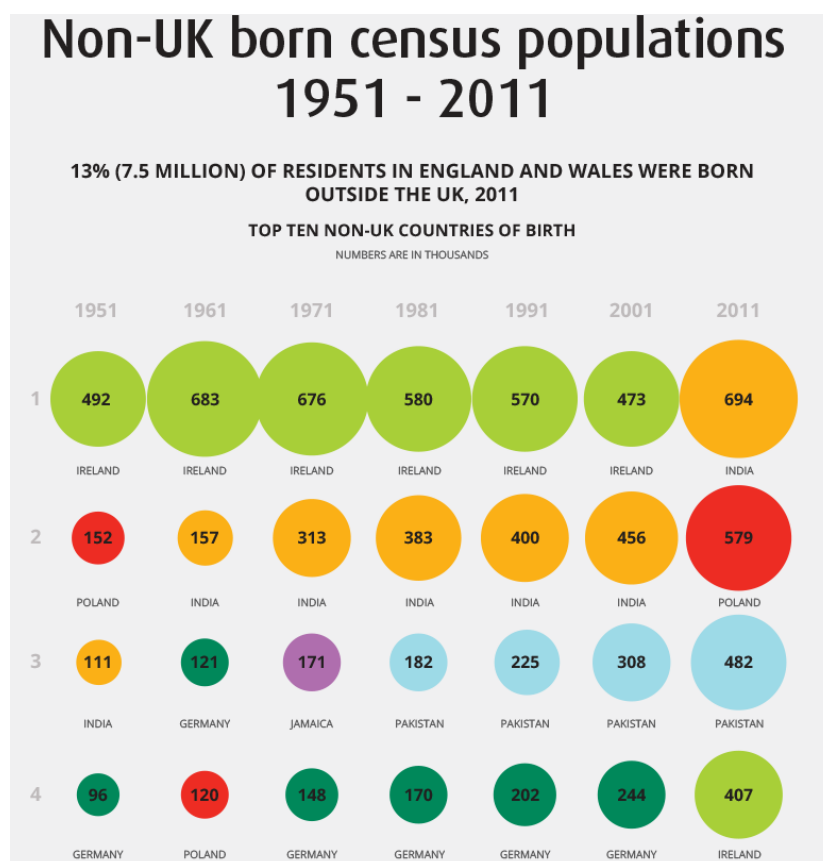


Figure 4: Census data on top 4 migrant groups by country of birth - across England and Wales from 1951-2011 – the fluctuating nature of migrant groups over time can be seen - [taken from ONS 2012]

Migrant groups may face a higher burden of disease, compounded by known inequalities in healthcare access and quality. Migrant health is complex, and related to multiple determinants across

socioeconomic, cultural and environmental conditions that consider the political and social context, as well as individual characteristics; and considers these concepts across the host nation and country of origin [WHO 2010].

CVH carries a global risk burden, with a risk profile that is unknown in the newly arrived Nepali community. In developing a strategy to engage with this new population, and in trying to optimise CVH testing and linkage to care across the healthcare system, it is important to first gain an understanding of the broader determinants of health that may affect this newly arrived population, and how these factors may influence our current research testing objectives, and future health engagement in the UK Nepali community. To this endeavour, the following section presents an overview of the Political, Social and Health aspects affecting migrant communities, and a more detailed assessment of potential CVH risks that may be seen in migrant communities, and the need for study in the newly arrived Nepali communities.

Political impact of migration:

Net UK migration rates in 2014 were close to the peak levels of 320,000 seen in 2005 following EU expansion, with rising rates of migration from within and outside of the EU [ONS 2015]. Net migration has been a target of senior politicians since at least 2011, with commitments and initiatives issued to bring (net) migration to within the “tens of thousands” per year [Eurostat news release, March 2015, Guardian, Taylor M 2015]. However, only recently has net migration fallen, associated to the EU referendum and looming Brexit uncertainties [Guardian November 2017].

Indeed, it is likely that rising anti-migrant sentiment played a part in the EU referendum outcome in the UK [Independent June 2017], with migration that has had a particular focus in political campaigns and in the pressures felt by the two mainstream political parties this decade. Migration was a key political factor in the 2015 election campaign, and was labelled as the 2nd most important issue to voters behind the NHS; and the UK Independence Party (UKIP) accordingly took 12.6% of the UK vote in 2015, and despite having only one MP maintained a large political profile in the run up to the 2016 EU referendum [Financial Times 2015, Guardian May 2015].

Likewise, across Europe there has been a surge in support for nationalist political parties with far-right sympathies over the last two decades (figure 5) [BBC May 2016], with mainstream commentary that Europe has taken “a right-turn” over the last decade, with EU communities perceiving an economic, social, religious and cultural threat from migrant populations and religions (namely Islam) [Wikipedia, List of Active Nationalist Parties in Europe; Economist 2014]

Rise of nationalism in Europe: Results of most recent national elections

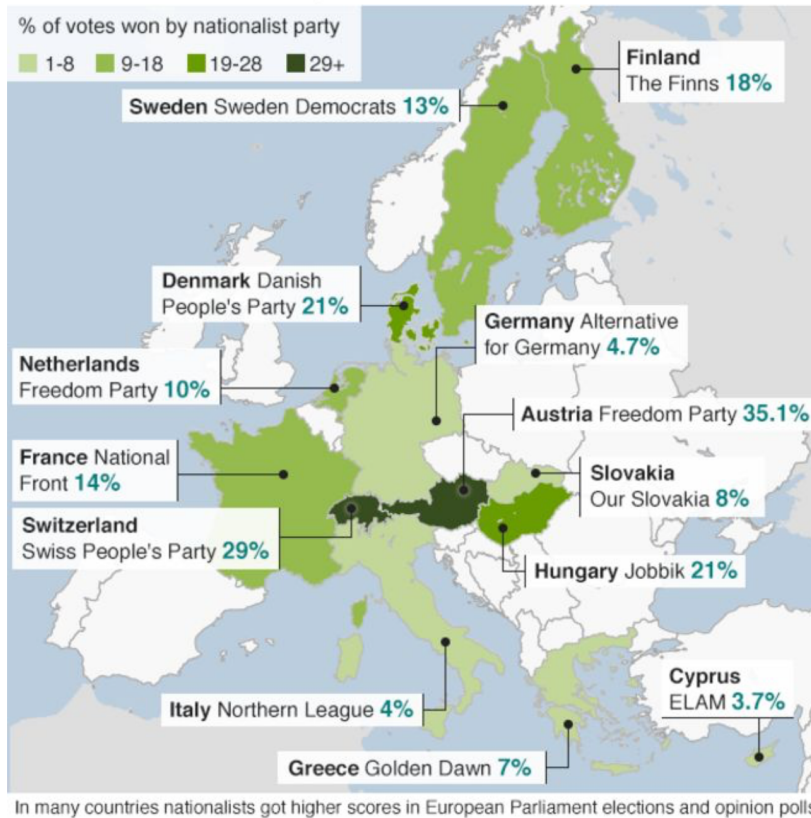


Figure 5: vote shares as received by nationalist groups across Europe in 2015/16; taken from BBC news [BBC May 2016]

In the UK, the rise of UKIP has replaced much of the focus and support for other recent far-right groups, including the British National Party (BNP) and the English Defence League (EDL), both with more extreme and explicit anti-immigrant and anti-Islam ideologies. Electoral support for UKIP is principally thought to be in relation to threats seen through the changing demographics from migration, as well as political disengagement from the main political parties in the UK, particularly amongst White, working class individuals [Guardian April 2014, YouGov April 2014]. And whilst some of the political rhetoric over the past few years from the governing parties may need to be seen as a response to this surge in UKIP popularity, some actions such as the use of buses advertising “go-home” to illegal migrants by the conservative party have been strongly criticised across the spectrum, even by Nigel Farage, the then leader of UKIP [Guardian July 2013].

From a health perspective, Nigel Farage received significant amounts of media coverage for his focus on health tourism in migrant individuals, and in particular his focus on HIV, using the live political debates of 2015 to label higher rates of HIV infection in migrant communities. He focussed on using HIV above other health conditions, which was reported as pre-planned in its attempts to promote a shock-effect, and galvanise like-minded UKIP supporters rather than a spontaneous comment [Telegraph July 2015]. Similar high-profile comments by the previous UKIP leader have been made

over the past few years, to highlight higher rates of TB, HBV and other disease in migrant groups, and to lobby for entry checks and refusal options to migrants trying to enter the UK, as well as measures to refuse treatment to non-British citizens in the UK. Such comments have been promoted by some media outlets, and the Daily Mail ran its' own commentary piece: "Immigrants in the NHS; HIV and the true cost to the NHS: Should the "International Health Service" be treating patients who come here with the killer disease?"; in which the journalist uses the higher number of foreign faces and voices in an inner city London GUM (Genito-urinary medicine) clinic to link these and most migrants towards health tourism and HIV testing [Daily Mail October 2014]. Such articles and supportive related social media comments highlight the provocative and stigmatising nature of comments from UKIP and other right-leaning political sources, as well as the flawed generalisations of data and stereotyping used by these groups to justify concepts of health tourism, for which contradictory evidence exists both from the House of Commons report of 2005 and the National AIDS Trust [Guardian April 2015].

In recent years, the Conservative government has taken steps to introduce (£35K) pay-caps to non-EU migrants seeking UK residency, as well as NHS user fee charges applied to non-EU migrants without settlement rights, and has publicised drives to keep only the "best and the brightest" migrants in the UK [BBC February 2012, Guardian June 2015, The Migration Observatory 2011, Guardian November 2014, Home Office 2013, Bowsher G 2015]

Overall then, the explicitly negative focus taken towards migration over the recent years seems a step-change in comparison to the political view taken over the last two decades. And whilst the UK government is clear that it is not against all forms of migration, and emphasises the value and contribution that it can bring; it remains to be seen how this negative focus impacts the known health inequalities that migrant groups face, and the broader socio-economic, cultural and environmental conditions that effect the health and health engagement in migrant communities (figure 6).

Social aspects of migration

Migrant groups are hugely diverse, and individuals may be considered as migrant workers, students, refugees, asylum-seekers (including failed asylum applicants), family re-union migrants, trafficked persons and undocumented migrants [Aspinall PJ 2014]. Government policy is an important driver in migration, but the influences behind overall migration trends are multifactorial, with economic and labour market forces the principal drivers of international migration [The Migration Observatory May 2015]. In the UK, work is the most commonly cited reason for travel by non-UK citizen, although in non-EU individuals study becomes a more prominent factor, presumably in relation to government policy on visa restrictions to non-EU migrants. Most UK citizenship is however granted for work

reasons, and economic and labour market considerations are therefore key aspects in UK migration [The Migration Observatory May 2015].

Migration trends are more complex however than labour supply alone, and the UK has a strong history of migration from former colonial states, with many individuals who started to arrive in the UK from the 1950's and 60's from the Caribbean and South Asian countries. Once migrant communities are established, they can in turn facilitate further migration through transnational ties and migrant-networks, encouraging and easing the process for new arrivals. Indeed these associations are likely to account for the relatively high level of migration seen from post-colonial South Asian countries over the past few decades, and for the steady distribution of countries contributing to UK migration over the same period (figure 3) [Czaika M 2013]. Accordingly, new migrant communities may face particular challenges over established communities, with limited migration-networks in place to support settlement and integration, and therefore may be more vulnerable with regard to access for employment, housing and healthcare access.

Within the UK, most migrant communities are closely clustered in certain geographic areas. Such clustering may be manifest of the support gained from migration-network links, as well as available housing and employment opportunities for these individuals. Some areas, such as that in East London have served as centres for new-migrant arrivals, from Jewish settlers to members of the South Asian community, whereas other areas in Eastern England have only recently become popular sites for migration of Eastern European migrants. Clustering of migrant groups can lead to rapid or generational changes in the pre-existing native community, provoking ethnic tensions that can rapidly flare, as seen in the Oldham riots of 2001 [BBC news 2013, Wikipedia 2015].

Integration of migrant groups into society is a complex area, with multiple definitions used to characterise and measure integration as well as a paucity of data collection, which is most lacking in new migrant communities. Societal integration is therefore best described in established communities, but even here there are differences in how integration is viewed, whether as "assimilation", or perhaps more inclusively and appropriately defined as "a series of processes relating to participation in the labour market and social institutions (such as education), social interaction and civil participation" [The Migration Observatory 2011]. Such broad variation in how integration is viewed may relate to lack of central strategy to address integration, but also reflects conflict at the societal level on the impacts of migration. From a policy perspective, there are frameworks which exist to try and facilitate integration for refugees, and following the conflicts seen in Oldham and surrounding areas in the early 2000's, there is now a citizenship programme for those seeking settlement in the UK. However for new migrant groups, there is no structured approach to guide or

facilitate societal integration. These groups may be further hindered by language or cultural barriers, and reduced support from existing migrant networks that limit awareness and access to employment and services, including access and uptake of health services, particularly in first-generation migrants.

At a socio-economic level, migrant individuals have poorer outcomes overall with regard to labour participation, unemployment and over-qualification compared to native born individuals across Europe. Lower income levels are also documented for non-EU migrants, with the increased risks of poverty, social exclusion and overcrowding that are co-existent to this. First generation migrants are at particular risk from these outcomes, and new-migrant populations perhaps even more so, although collective information for this group is limited in relation to established migrant communities, who are more likely to be in work and educational settings [Eurostat 2011].

As such, individuals from migrant communities are often considered vulnerable, and whilst there is very wide differential in socio-economic status amongst migrant workers, individuals from these groups are overall at increased risk of many determinants of health and wellbeing, including education, employment, housing and access to services.

Health in migrant communities:

Health disparities are widely reported in migrant communities, with ethnicity typically used as the identifying characteristic in disease prevalence and health inequality studies. New migrant groups are therefore typically underrepresented in these studies, as ethnicity definitions are usually tailored toward the existing minority communities [Jeyaweera H 2010].

Avoidable inequalities in the health status of migrants, as well as the quality and accessibility of services for migrant groups have been reported across the European WHO region. These inequities have been related to social determinants of health, and social exclusion in particular, with individuals, households or communities excluded from access and engagement in health services. This social exclusion may be the result of unequal power distributions across economic, political, societal and / or cultural grounds, with individual or institutional discrimination eroding the self-empowerment and ability of groups to manage their health effectively [WHO 2010]. Socioeconomic status is an important consideration and likely co-factor in health inequities in migrant groups, and certainly lower socioeconomic status in arriving migrants would account for risks including overcrowding, nutrition and poor sanitation, as well as risk behaviours, including drug use and sexual practices that would increase the risk of BBV in these groups. There is however clearly more to health inequities than socioeconomic status alone [Marmot M 2017], with individual risks, cultural practices that may be

associated with disease or wellness states, the background prevalence of disease in the country of origin, as well as an additional socio-economic burden that many migrant groups face on arrival to the host country that is independent of their background and educational status [WHO 2010, Ingleby D 2012, Eurostat 2011].

An illustration of these complex relations, and the modifiable nature of these interactions is explored and demonstrated in the social determinants of health model, utilised and championed by international bodies including the WHO [WHO 2003]. The social determinants of health explore the political, social, economic and environmental forces that influence how people are born, grow up, live, work and age; influencing health inequalities. The model considers multiple layers including socio-economic and environmental conditions, social and community networks and individual and lifestyle factors, as illustrated in the (adapted) Dahlgren-Whitehead representation in figure 6. Migration is then an additional layer to this complex relationship, with the status and determinants of the individual in their origin-nation interacting with the determinants in the new host country acting to potentially improve or worsen health and health inequities [IOM 2006, WHO Health Impact Assessment].



Figure 6: **The Determinants of Health (1992) Dahlgren and Whitehead** **Modifiable factors** that influence health at the personal (including predisposition), environmental and societal level [image taken from NHS Scotland, Bridging the Gap]

Accessible health services are often lacking for migrant communities, with a lack of awareness of existing facilities, and a mismatch in the provision of language and culturally appropriate services for these groups. Perceptions towards healthcare are known to vary in migrant groups, and newer communities may be unfamiliar with preventative strategies in healthcare or broader models of Western healthcare provision. It may also be that the migration process itself influences healthcare access and uptake, with “official” migrants perhaps more visible and likely to engage with healthcare

services [Davies A 2010]. Multiple factors are likely to influence healthcare access and uptake in migrant communities, with previous reports that identify six key factors to be considered: the legal entitlement of migrants, knowledge and awareness of the healthcare system in the new country, previous experiences of healthcare, language and cultural barriers, health beliefs and attitudes, as well as the structure of the healthcare system in the host country [O'Donnell CA et al. July 2015]

Migrant groups across Europe and the UK are heterogeneous in nature, but are generally younger than the native population, and most migrant groups are healthy and active contributors to society [Fitzpatrick J 2005]. Nevertheless, certain chronic disease states and infectious diseases are identified more frequently in some migrant groups. Disease states may be linked to exposure in the country of origin, cultural practices, as well as environmental risk-factors in the host country on arrival (e.g. smoking, diet, alcohol or drug-use). In the UK, chronic disease states such as cardiovascular disease and diabetes are more common in members of the Pakistani and Bangladeshi communities, which are likely related to environmental exposures (e.g. diet, smoking) as well as pre-existing risks. There are also differences in health perception, and service utilisation in some migrant groups. And whilst, socioeconomic status may account for some of these differences, it is likely an oversimplification to account this factor alone in relation to these associations [Ingleby D 2012, Health Survey for England 2004].

Among the infectious diseases that may be seen in higher proportion in UK migrant groups, Tuberculosis, Malaria and Blood Borne Viruses, including HIV, HBV and HCV are perhaps the most commonly cited. Estimates for these disease risks are frequently extrapolated from sentinel laboratory data by PHE (Public Health England) or research studies, and there are risks therefore in generalising or stereotyping intrinsically heterogeneous groups. However, it remains important that these risks are acted upon to improve our risk stratification, and crucially to identify and treat those individuals who would otherwise go undetected [Ingleby D 2012].

Many disease states produce symptoms that may facilitate diagnosis in an early stage, but some diseases such as chronic Hepatitis B and C (HBV and HCV) infection produce little in the way of symptoms until advanced and potentially fatal complications have set in. Migrant groups in the UK have higher rates of HBV and HCV based on sentinel surveillance and research studies. Delivering testing in migrant communities therefore becomes of paramount importance to bring people forward for treatment, as well as preventing the spread of infection further in the wider community.

HBV and HCV in migrant communities: potential impact and the need for study

Hepatitis B and C (HBV and HCV) are blood borne viruses (BBV), which target the liver with the risks of progressive scarring (cirrhosis), liver failure and primary liver cancer. The prevalence of HBV and HCV is low in the background UK population, but is disproportionately higher in certain at-risk groups, linked to geographic variation, iatrogenic exposure and risk activity. The health impacts of HBV and HCV can be severe, with significantly increased morbidity and mortality in those individuals who progress to end stage liver disease without effective treatment. Indeed, HBV and HCV are the leading cause of cirrhosis and liver cancer worldwide with close to 390,000,000 individuals thought to be affected, and 1.46 million deaths registered worldwide in relation to CVH in 2013, with comparable mortality rates to that seen with TB and higher than that seen with HIV; but with a lower global priority and public recognition [WHO May 2016]. In the UK, liver disease was the 5th leading cause of death, with chronic viral hepatitis one of the leading drivers for this, behind alcohol [Davies SC 2012], and remains a global priority for control and eradication by 2030 [WHO May 2016].

Although both HBV and HCV are blood borne viruses, and carry the same generic risks of disease transmission, there are differences in the likely routes and patterns of this transmission, as well as the risks of chronicity in affected individuals.

HBV is around a hundred times more infective than the HIV virus, but with vertical transmission rates from mother to child that may be as high as 90%, coupled with perinatal or childhood acquisition that are the main drivers of the endemicity of HBV seen globally (figure 7). HBV may be also transmitted sexually, as well as potential risks with the sharing of razors or toothbrushes in some circumstances [Foundation for Liver Research 2004]. Not all affected individuals become chronic carriers, with age a particularly important risk-factor for HBV, with neonatal and perinatal exposure leading to chronic infection in over 80-90% of cases, and adult exposure that may lead to chronicity in only around 5% of cases [Hyams 1995].

HCV is transmitted principally by exposure to contaminated blood or body fluids, with injecting drug use thought to account for up to 90% of cases in the UK [PHE 2013]. Vertical transmission is less well defined, but likely to be an important factor on a global scale, with perinatal transmission risks that may be towards 6% [Benova L 2014], and with household transmission that is not widely recognised. The risks of chronicity again vary with age, but are less marked; with around 75-80% of all exposed individuals developing chronic HCV infection, and with chronicity that may be less likely in younger individuals as compared to older individuals.

Epidemiology of HBV and HCV:

There is marked geographic variation in Hepatitis B (HBV) and Hepatitis C (HCV) worldwide, particularly for HBV, which is endemic to certain parts of the world. Prevalence data is lacking in many countries, particularly in those with deprived health infrastructure systems, but overall across Europe reported rates of HBV and HCV infection are between 2-6 times higher in migrant groups than that seen in the existing population [Hahne 2013].

HBV prevalence:

Globally around 350-400 million individuals are thought to be affected by HBV [Sharma S 2015], and HBV is endemic in some parts of the world (figure 4); with endemicity defined by a prevalence rate > 8%, moderate endemic countries having prevalence rates of 2-7%, and low prevalence countries with rates <2%.

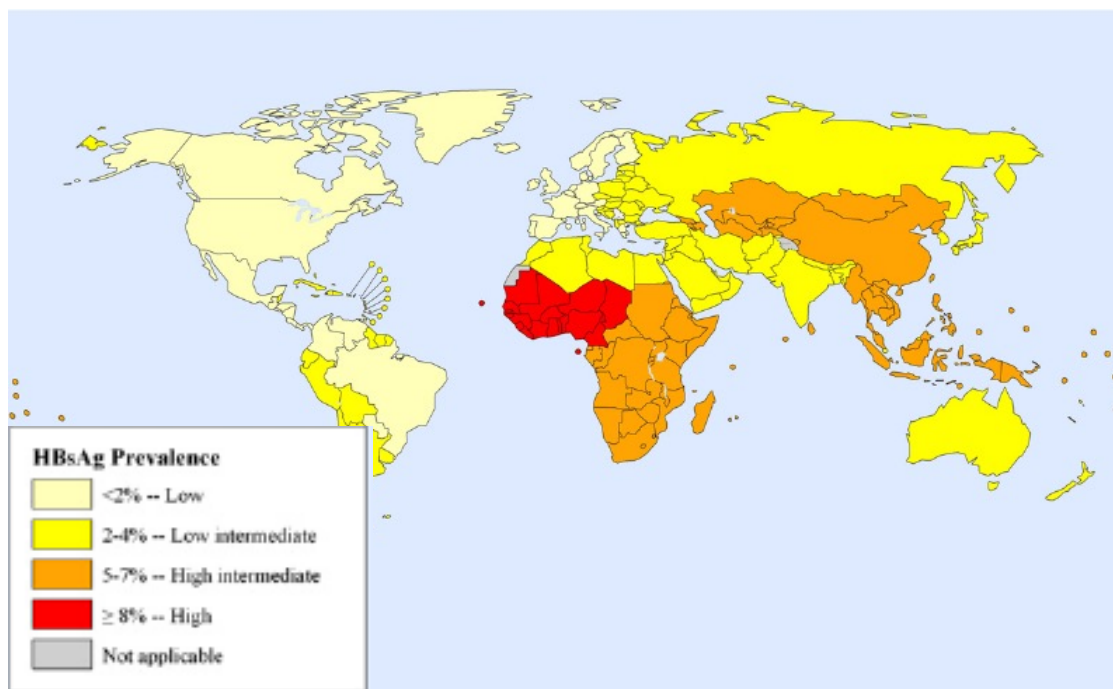


Figure 7: Estimated global prevalence of HBV infection in adults 19-49 yrs; up to 2005 [adapted from Ott J, 2005]

As shown in fig 7, Western Europe including the UK has low HBV prevalence rates (<2%), whilst parts of South-east Asia and Sub-Saharan Africa have high rates of HBV, between 10-20%. It is estimated that up to 80% of people in regions of sub-Saharan Africa and Asia have been exposed to HBV, as compared to <15% of people in regions of Europe and the USA [Thomas 2012]. Vertical transmission

is thought to be the predominant route of transmission in China, whereas horizontal transmission in the first few years of life is thought to be the main route of transmission in Africa [Dooley 2012].

In developed countries such as the UK adult acquisition of HBV tends to be the result of high-risk activity (mostly sexual activity), with the burden of new chronic HBV disease being the result of migration of persons from endemic, or higher risk regions. Prevalence risks have been estimated to be higher across many different migrant groups, with Hepatitis B surface antigen positivity reported as close to 13% in East Asian migrants in the US [Sharma S 2015].

Hepatitis B rates in the UK:

For both HBV and HCV, there is uncertainty about the exact number of cases that have been diagnosed or treated in the UK [Ramsay M 1998]. Apart from antenatal HBV screening there is no national screening policy for viral hepatitis (B or C). Incidence and prevalence rates (for both HBV and HCV) are therefore derived from several sources including research studies, antenatal screening, and the sentinel surveillance blood-borne virus testing programme (SBV), which collects demographic information on viral hepatitis and testing results across certain designated laboratory sites in England.

The most widely used estimates of chronic HBV infection in the UK arises from Department of Health (DoH) data in 2002, with prevalence rates of 0.3% and an estimated 180,000 affected [Department of Health 2002; Getting Ahead of the Curve], but there is variation in this estimate with some experts placing this figure close to 500,000 [NICE press-release 1].

Importantly, up to 95% of new chronic HBV cases in the UK occur in migrant individuals, with most individuals who would have acquired Hepatitis B in early childhood in the country of birth [NICE 2012]. Rates of HBV are also consistently higher in those individuals recorded to be of Asian British (AB), Black British (BB) or Other Mixed (OM) groups from previous sentinel laboratory data; with 8.9% of BB individuals testing positive compared to 6.9% of OM individuals, 2.8% of AB individuals and 0.9% of WB (White British) individuals in non-antenatal testing samples. Further information from blood donor testing shows that of 91 positively identified HBV cases, 60% of patients were born in Africa or Asia [HPA Migrant Health 2011].

Chronic HBV predominates in the positive cases identified, and given the asymptomatic nature of HBV, there is likely to be a large pool of undiagnosed HBV infections that would not be reached without a targeted testing approach [HPA Targeting Testing, 2011].

HCV prevalence:

Approximately 2-3% of the world population (160 million) are thought to be infected with chronic HCV [Lavanchy 2011], and whilst prevalence data is lacking or underrepresented in many countries, there is marked geographic variation in prevalence rates worldwide (figure 8).

Most European countries report chronic HCV prevalence rates between 0.5 - 2%, although Italy has rates as high as 3.9%. Egypt has the highest reported chronic HCV rates with rates quoted between 20-30% [Hyams 1995, WHO 2002], which is thought to be secondary to an iatrogenic schistosomiasis programme. One of the largest HCV populations is thought to be in East Asia and the Indian subcontinent, with an estimated 100 million HCV positive individuals in this region, and with prevalence rates of 4.9% reported in Pakistan [Sharma S 2015]. Parenteral spread through iatrogenic procedures, such as blood transfusions, surgery and unclear needle use, as well as injecting drug use are thought to have contributed to the rapid spread of HCV in the 20th century; but with the underlying recognition that there is a natural geographic variation in HCV that pre-date these factors [EASL 2013].

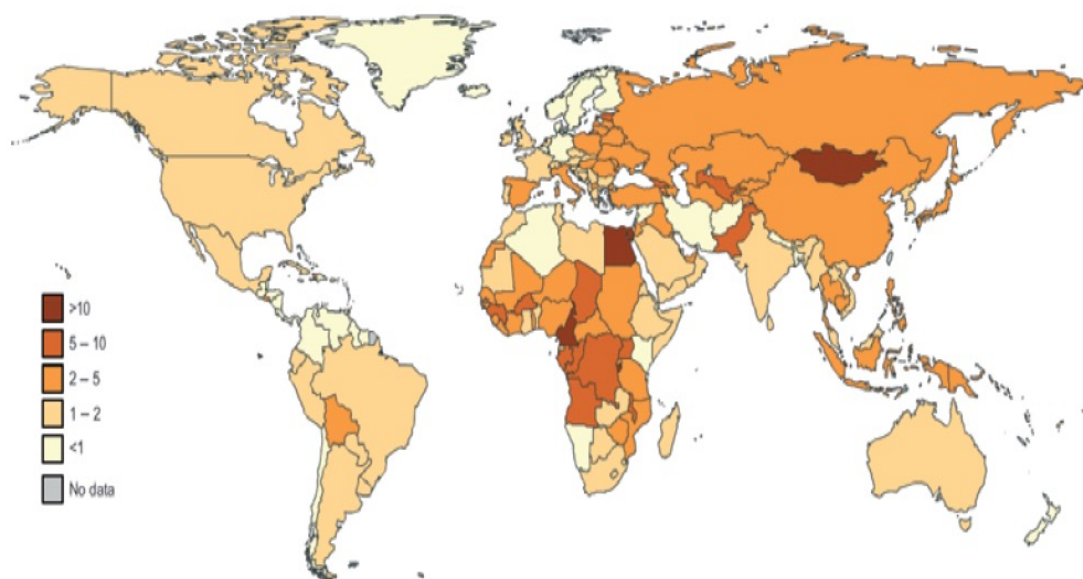


Figure 8: Global distribution of chronic HCV (%) – taken from Lavanchy 2011

HCV rates in the UK:

Within the UK around 215,000 individuals are chronically infected with HCV, with 160,000 (0.4% prevalence) cases in England and 38,000 (0.7% prevalence) in Scotland. HCV exists in distinct genotypes, with genotypes that are more common in some parts of the world. Genotype 1 and 3

predominate within England, with Genotype 3 and 4 patients often seen more commonly in some migrant groups, including the South Asian population and migrants from Egypt.

Injecting drug use is the biggest risk factor for chronic HCV in the UK, but HCV is disproportionately higher in migrant groups, particularly in those from South Asian origin (Indian, Pakistani or Bangladeshi origin) and Eastern Europe compared to the non-injecting White British population. Data from the sentinel surveillance programme shows a HCV prevalence rate of 2.7% in Asian/Asian-British individuals, and although there is no categorisation for those of Eastern European origin, post-hoc name recognition software has shown prevalence rates as high as 5.4% in this groups of patients [PHE 2013].

Importantly, it is estimated that between 50-75% of patients with HCV are unaware of their infective status. The majority of chronic HCV therefore exists undetected in the community, with projected morbidity and mortality that is expected to rise in this undiagnosed population [PHE 2013, Williams 2014].

Natural history of CVH infection:

Chronic HBV and HCV infection may cause atypical symptoms or remain asymptomatic until complications develop, with cirrhosis and hepatocellular carcinoma the most feared, as well as other systemic complications (such as cryoglobulinaemias) that may also be seen with CVH. These complications may develop over decades, with treatment decisions are directed in the UK through specialist hospital services.

Around 15-40% of chronic HBV patients are thought to be at-risk of progression to cirrhosis or hepatic decompensation [Dooley 2012], and HBV may have its own independent risks in the development of HCC (hepatocellular carcinoma); albeit at a significantly lower rate than that seen in cirrhotic individuals [Do AL 2014].

For HCV the risks of developing cirrhosis in chronic infection is reported to be close to 20% at 20 years, rising to 36-45% at 30 years [Thein 2008], with chronic HCV infection now one of the leading indications for Europe and North America [WHO March 2015, World Gastroenterology Guidelines 2013].

Whilst not all patients with HBV may require treatment initially, highly effective and cost-effective treatments exist overall for CVH, with a treatment revolution in HCV that has now been translated into most developed health systems worldwide. These developments, in conjunction with HBV vaccination goals have led to global and national initiatives calling for CVH to be eradicated as a public health threat by 2030 (with a 90% reduction in new chronic infections, and 65% reduction in mortality)

[WHO May 2016, Williams R 2014]. Treatment is highly efficacious if delivered at the right time, to reduce or prevent the development of cirrhosis or primary liver cancer with significant individual, and health system savings.

Current case-finding practice for CVH:

For HBV and HCV, case-finding is internationally recommended in at-risk individuals (figure 9) [Del Poggio, 2006], and forms the basis for NICE testing recommendations published in 2012 [NICE 2012]. The aims of such a testing programme are to identify at-risk groups, as well as to bring patients forward for therapy if disease is detected [NHS England 2015; Ruf M 2008].

Identification:	Identifying the at-risk group / individual within the background population, - based on the “visibility” of this group, including social exclusion factors
Engagement:	Develop methods of engagement for awareness-raising and testing Culturally-appropriate interactions Based on perceptions of health (stigma) and healthcare services
Testing:	Develop effective methods to deliver testing, which may relate to: Accessibility and Awareness Tolerability and efficacy (sensitivity, specificity) Available treatment pathway (if positive)

Figure 9 – The dynamic and active processes involved in effective case-finding activity

In the UK, policy exists to recommend CVH testing in migrant groups through the national institute for health and care excellence (NICE), with community testing the aim of these public health recommendations; and primary care the principal agent to deliver testing to migrant groups in the community (as explored in the following chapter). Our knowledge regarding the awareness and uptake of this policy is limited, particularly in primary care, and is one of the key aspects to be explored in this thesis. However, the historic understanding and uptake of (prior) national CVH policy endeavours has been low in primary care [D’Souza RFC 2004, RCGP 2007], with studies that continue to show a low priority afforded to CVH in primary care, and low levels of testing that is thought to continue in at-risk groups in primary care, including migrant communities [Jewett A 2015, Datta S 2014, Evlampidou I 2016].

HBV & HCV risks in new migrant groups

Within migrant populations, new migrant groups may be particularly vulnerable with regard to healthcare. Accessible healthcare services for these groups are typically limited, with most existing services designed around established minority groups [The Migration Observatory 2014]. Diminished migrant-networks in the new community, as well as language and cultural barriers may impact the

awareness of health services, and there may be perceptual differences in how health and disease is viewed in these new communities, as well as the need and importance of healthcare engagement. New migrant groups may also face socio-economic difficulties through housing, education and employment that increase their social exclusion and further erode self-empowerment, as well as perhaps introducing new risks through overcrowding and environmental risks, particularly in the most marginalised groups [WHO 2010]. The existing health monitoring systems are also limited in new migrant groups, with the routine use of ethnicity data that may mis-code new communities, or fail to identify them at all.

For HBV and HCV, first generation migrants and those in new-migrant communities may be at particularly risk, with higher rates of cirrhosis and primary liver cancer that have been noted in this group [HPA South East 2011, Haworth 1999]. Developing testing strategies to identify and engage with new-migrant groups is therefore a priority within migrant testing, and an area that often receives little attention.

Understanding the health needs in new migrant communities, and developing engagement strategies to assess these risks is therefore important, with a global burden of CVH and highly effective and deliverable treatments that necessitate an exploration of CVH risks in new migrant communities such as the UK Nepali community.

The UK Nepali population; a new and unique migrant community:

The UK Nepali community represent such a new migrant group, with a population that has grown by over 969% from 2001 to 2011, following settlement rights granted to ex-Gurkha servicemen and their dependents in 2004 and then 2009 [ONS 2011 census data, CNSUK 2013]. Given close military ties, this community has clustered around traditional army sites, with the result that the areas around Aldershot, including Frimley Park Hospital (where I undertake my clinical duties) have now acquired the 2nd largest Nepali population in the UK (outside of London). The migration of these ex-servicemen and their dependents has produced a rapid change in the baseline community, with Nepali migrants said to make up between 6-10% of the local population in some council-administered areas [Telegraph 2011].

Political context in Nepal:

Nepal is classified as one of the Least Developed Countries by the UN [UNDP 2016], and is one of the poorest countries in Asia with an estimated 40% who live in poverty [World Bank 2015], and with an average life expectancy of 68 years [WHO Global Atlas 2014]. The Human Development Index (HDI) is a global index that attempts to measure the development of a country based on the potentials and capabilities of its population (over economic growth alone), and utilises an average assessment of life

expectancy at birth, years of schooling, and gross national income per capita [UNDP 2014]. On this measure, Nepal performs just above Afghanistan in comparison to other South Asian countries, with the additional difficulties of significant variations in HDI measures that are seen geographically within Nepal, seemingly based on divides in ethnicity, caste and religion [UNDP HDI 2016]. Most of the population depend on agriculture, which employs an around 80% of the population, with tourism also important; with Nepal offering eight of the ten tallest peaks in the world amongst other UNESCO heritage sites. Foreign aid though remains vital, particularly following the catastrophic earthquakes of 2015 [BBC Nepal 2015, Time April 2015].

Nepal has strong and unique links to the UK, with Gurkha military recruitment to the UK Armed services that extends back to the early 19th century. Nepal was not however a formal colony of the UK, and migration patterns from Nepal differ to the other South Asian countries (India, Bangladesh and Pakistan) in the UK, with restrictions that applied to many Nepali's during the reign of the monarchy before 1990 [Washington Post March 2014]. Nepal has therefore remained relatively isolated compared to its South Asian neighbours, with According to the 2001 census there were close to 6,000 Nepali resident in England and Wales, a figure that has grown dramatically since, with an estimated 80,000 Nepali resident in the UK in 2012 [CNSUK 2013]. This growth has been driven by Gurkha settlement rights introduced first in 2004, and expanded in 2009 to allow retired Gurkha soldiers and their dependents (<18 yrs) the right to settle in the UK [BBC May 2009].

Politically Nepal has experienced much volatility with significant gaps in effective national, regional and local governance infrastructure that was readily exposed in the devastating earthquakes of 2015 [Washington Post April 2015]. Years of Maoist insurgency ended in 2006, with abolition of the monarchy in 2008, but with a national constitution that has yet to be agreed over the seven year interim period, highlighting the conflicts and inefficiencies that exist in the current system [The Hindu 2015]. Emigration from Nepal has therefore increased as a result of political indecisions, poor infrastructure and employment opportunities, with close to 10% of the population now working abroad, typically in low-skilled jobs [Washington Post 2014].

Gurkha recruitment on the other hand has continued largely undaunted since the early 19th century, following initial recruitment of Gurkha soldiers by the East India Company. Gurkha recruitment has traditionally occurred from certain castes, and the UK Nepali community is drawn almost exclusively from 15 out of the total 75 districts in Nepal as a result [CNSUK PPT 2013]. Becoming a Gurkha officer is one of the most prized positions in Nepali society, with a prestigious salary and pension that can transform families' lives, and with competition rates far higher than entry to the UK Army [Telegraph

March 2014]. Traditionally Gurkha soldiers were recruited and discharged as Nepali citizens, with a British base that was in Hong Kong before moving to the UK in 1997.

It was only in 2004 that the (then) Labour government provided settlement rights to Gurkha soldiers; initially restricting this to those soldiers who had retired after 1997. However servicemen who retired before this period were not granted UK settlement rights, and extensive lobbying from the Gurkha Justice Campaign and most notably by the celebrity Joanna Lumley pressured for this policy to be expanded. The campaign achieved widespread publicity and support from liberal and right-minded media sources alike, with the Labour government eventually overturned in its settlement restrictions in 2009, with support from the Liberal Democrat and Conservative parties [Daily Mail 2008, Guardian 2009]. Financial support for the settlement of ex-Gurkha servicemen has however been widely criticised by the responsible councils, who have managed a clustering of new residents during the austerity period, with a cut of £2.4million reported to the Rushmoor council budget in 2011 [Telegraph 2011].

Social aspects of migration in the Nepali community:

There are over a 100 caste / ethnic categories in Nepal, with several religious affiliations that generally pursue harmonious interactions. Hinduism is the most common religious affiliation, with Buddhism, Islam and Christianity also seen. The majority of people live in rural areas, with many who occupy hilly or mountainous terrains where road links will be limited or non-existent [Rural Poverty website].

There UK Nepali community is drawn predominately from ex-military servicemen and their dependents. Data in the UK community is limited, but studies from the Centre for Nepali Studies UK (CNSUK) in the Aldershot area looking at the date of military discharge demonstrated that those servicemen discharged in the late 1960's and early 1970's with an average of 65-67 years have significant issues in literacy and economic contribution compared to their younger compatriots. Older male servicemen in late 60's (67 years) were found to be functionally illiterate even in Nepali, and therefore with reading and writing skills in Nepali that would be inappropriate for most work settings, and Female dependents were particularly limited from a literacy perspective, with the vast majority (94%) of those over 60 years' illiterate in Nepali [CNSUK PPT Laksamba 2013]. This suggests that many in the recently arrived community may face disadvantages in the social determinants model, and may face challenges in accessing conventional health care services [CNSUK PPT Laksamba 2013].

Social exclusion in this subset of the community is therefore a particularly strong concern, with many new Nepali-migrants thought to be in this older category. Indeed media reports over the past few years have focused negatively on the numbers of elderly Nepali migrants seen in the Aldershot area

in particular, with socioeconomic concerns raised about welfare support and sub-optimal housing in many older individuals, who have pensions designed and issued by the UK government to provide a high standard of living in Nepal, and pensions in these older Gurkha veterans are not matched to UK servicemen [Daily Mail November 2014]. It may also be that women, particularly Nepali migrant widows may be less able to access and engage with services due to language restrictions that seem substantially higher than that seen in the age-matched male population. Some elderly Nepali have commented that they were enticed to move to the UK for a better life with promises of jobs and employment, but have found their reality very different. Media reports have also commented upon the hostility faced by members of the Nepali community, with perhaps the most vocal comments towards elderly Nepali migrants made by the Aldershot Conservative MP, Sir Gerald Howarth [Huffington Post March 2012], including the comment that:

"I was walking around in Aldershot on Saturday and everywhere I went there were Nepalese just basically sitting out in the open, sitting out on the park benches....."

"You may find this bizarre, but some of my constituents say 'if I go into town, I haven't got a park bench to sit on because they are all taken by the Nepalese'."

These comments seem directed mostly at the elderly Nepali community, who conversely would seem the most at-risk for social exclusion, and given their age the group most at risk for health complications, including from hepatitis B and C.

Concerns about social exclusion in this group are supported in the Health Needs Assessment undertaken by Hampshire council in 2010, involving stakeholders from the local Nepali community, as well as healthcare practitioners and members of the education and Police force among others. Wider social determinants identified from these focus groups identified concerns about racism and bullying from members of the local community, concerns about overcrowding, including a lack of understanding amongst Nepali migrants how to access existing services in the UK, as discussed further below [NHS Hampshire 2010]

Health aspects of migration in the Nepali community:

There is no robust data on disease prevalence and health needs in the UK Nepali community, with our understanding of the health awareness, knowledge and perception in the community equally limited.

Following the initial settlement of Nepalese ex-servicemen in the Rushmoor district, a Health Needs Assessment was conducted by NHS Hampshire in 2010, with input from GPs, local clinicians, pharmacists and allied health professionals. Suggested risks and health needs were made based on the initial experiences of these health professionals, and public health information, with diabetes,

cardiovascular disease, and certain gynaecological cancers raised by these stakeholders. Among infectious diseases, Tuberculosis was identified as a possible risk from preliminary data, as well as Hepatitis B and C, albeit with low numbers of individuals tested at the time of consultation. Substance abuse in young males was also mentioned by members of the community, with these individuals smoking heroin [Casey M 2010].

The Health Needs Assessment also included focus groups in the Nepali community, with a combined presentation of the key health priority areas raised by stakeholders and by members of the Nepali community during focus group discussions. Whilst CVH appears as a potential (under-tested) risk in stakeholder discussions, it is interesting to note that HBV appears as a specific risk raised during focus group discussions in the Nepali community, but with no transcripts or further analysis provided by the authors to understand this expression and the reasons behind it (figure 10) [Casey M 2010].

General Practice High abortion rates Gynaecological cancers Typhoid Cholera Hepatitis C	Renal failure Somatisation of mental health issues	Military Malaria* Japanese encephalitis* Visceral leishmaniasis* Giardia* Hookworm* Ascaris* Endemic non venereal syphilis* Congenital abnormalities Auto immune disease (SLE and Rheumatoid) Post streptococcal glomerulonephritis
Asthma High cholesterol Cardiovascular disease Heroin Use	Diabetes Hypertension Tuberculosis	Peptic ulcer disease and dyspepsia Smoking and chewing tobacco
Hepatitis B Hypothyroidism Depression Alcohol use Cannabis Use Nepali Community		

Figure 10: Perceived common or important health issues to address in the Nepali community according to the different stakeholders. Members of the Nepali community thought HBV was one of the most pressing issues to address; taken from NHS Hampshire Health Needs Assessment 2010

Health Systems in Nepal

Healthcare services in Nepal are generally considered to be poor. Services are provided by public and private institutions, but with private out of pocket expenses making close to 80% of all health expenditure, and with limited facilities and treatments offered in public settings. Access to healthcare is also poor, with around 0.67 doctors and nurses per 1,000 population, and access to health services within 30 minutes that is available to less than 60% of those living in rural settings in Nepal [Mishra SR 2015]. Nutrition and sanitation services are also limited in places, thereby further affecting the poorest and most marginalised rural communities [Karkee R 2013, Water Aid Nepal].

Infectious diseases account for a greater burden, with up to 2/3rds of all health problems related to infectious disease reported in 2001 [Rai S 2001]. Average life expectancy in Nepal is 68 years, which has increased by 6 years in the period from 2001 to 2012, but “healthy-life expectancy”, with that free from morbidity is however 9 years lower at 59 years [WHO 2012].

Rank	Cause of death all ages Nepal (2002)	No of Deaths (000s)	Cause of death all ages 2012	No of Deaths (000s)	Change in rank (2002-12)
1	Perinatal conditions	24	Chronic obstructive pulmonary disease	17.2	↑
2	Lower respiratory infections	23	Ischaemic heart disease	17.1	↑
3	Ischaemic heart disease	23	Stroke	15.3	↑
4	Diarrhoeal illness	16	Lower respiratory infection	13.1	↓
5	Cerebrovascular disease	11	Diarrhoeal illness	6.2	↓
6	Chronic obstructive pulmonary disease	6	self-harm	5.6	↑
7	Hypertensive heart disease	6	Tuberculosis	5.5	↑
8	Tuberculosis	6	Diabetes	5.3	↑
9	Measles	5	Road traffic accident	5	↑
10	Road traffic accident	3	Preterm birth complications	4.7	↓

Table 1: WHO top ten causes of mortality in Nepal in 2002 and 2012; the burden of chronic (non-infectious) diseases seem to have risen over this period [WHO 2012, NHS Hampshire 2010]

HBV and HCV in the Nepali population – *the need for study*

Nepal lies between China and India, two countries with a higher prevalence of viral hepatitis. Rates of viral hepatitis may therefore be higher in the Nepali population. According to the WHO Global Policy Report, there are no official reports on Hepatitis B and C rates from Nepal, and with no regular surveillance programmes that are in place in keeping with the known deficits that exist in health infrastructure within Nepal. There is no central policy to guide testing practice, and patients must pay for HBV and HCV testing as well as any necessary treatments, which may therefore impact (unmonitored) testing practice at multiple levels [WHO Global Policy Report 2013].



Figure 11: Map of Nepal

Available information on HBV and HCV prevalence in Nepal is limited to research from a few cohort studies, as well as blood donor analyses. Rates of active HBV infection have been reported in between 0.9% to 7.3% of individuals, with significant variations based on Nepali ethnicity, and with high rates of previous HBV exposure; seen in up to 35-44% of subjects [Shrestha S 2012]. For HCV, existing evidence is more limited with studies from blood donors that have identified rates that vary from 0.3% to 0.7% [Tiwari BR 2010, Karki S 2008].

The UK Nepali population is however unique, originating almost exclusively from set-districts in Nepal, and of certain ethnic groups; based on traditional Gurkha recruitment practices [CNSUK 2013]. There have been no studies of HBV and HCV in the UK community, and no studies with regard to health and healthcare perception in this new migrant community.

There are significant variations in CVH rates documented within and between migrant groups in some studies in the South Asian community [Uddin G 2010], and given the uncertainties and lack of study that exists in CVH risks in the newly arrived Nepali community it becomes important that these risks are understood through direct study.

The following study therefore attempts to understand the CVH risks that exist in the Nepali community, as well as the broader gaps that exist across the health system in how CVH testing can be optimised and delivered to all migrant groups, who share current political and social pressures that may adversely influence health access and engagement.

Chapter Summary:

Migrant communities face health vulnerabilities, including the global risks of CVH that require the delivery of effective testing strategies to understand and manage these risks, which will otherwise remain undetected until potentially fatal complications develop. The existing health infrastructure in Nepal is poor, with little knowledge of the CVH health risks in the newly arrived population, coupled with increased CVH risks that are seen in the neighbouring South Asian countries, and these migrant population groups in the UK.

At the same time, migrant communities across Europe are facing increasing anti-migrant sentiment, expressed at the political and social level, with migration a prominent feature in recent UK elections, as well as the lead up to the EU referendum.

The UK Nepali community is unique in its characteristics and context, and despite high-level public support UK settlement rights, is facing anti-migrant sentiments in the local political and social spectrum.

The effect of these determinants on migrant health with regard to health access and engagement is likely to be negative, with particular deficits that may be faced in new migrant communities such as the newly arrived UK Nepali population.

CVH risks can only be assessed and managed through effective testing strategies and linkage to health services, but with current testing practice and policy implementation that is broadly perceived to receive low priority, particularly in primary care services. It is imperative therefore to gain an understanding of the current gaps that exist across the health system in delivering CVH testing to migrant communities, and in developing a dedicated testing intervention to assess the risks in the Nepali community, who may otherwise not access or engage with current adhoc testing-practices.

Chapter 2

*Research methodology: aims & objectives and
research design*

Chapter 2 – Research Methodology: Aims & objectives and research design

Chapter introduction:

The following chapter presents an outline of the methodology used in the research study and research objective. An outline of the key research methods used to achieve these objectives is presented, with a more detailed description presented alongside each intervention study in the following chapters.

Research aims and objectives:

The principal aim of this study to identify the hepatitis B and C risks that exist in the local Nepali community; with an exploration of the potential facilitators and barriers that exist across the health system towards CVH testing in the Nepali community, as well as other migrant populations.

The chosen research objectives and methods used for assessment are built on the hypotheses (evidenced in chapter 1) that community CVH testing in migrant groups is likely to be poor, with particular deficits that are thought to continue in primary care, and with current CVH testing policy that is thought to have achieved limited recognition and priority in primary care, which remains the principal community agent to deliver wide-scale CVH testing to heterogeneous migrant populations.

The UK Nepali community is a recent migrant community, and may be more at risk with regard to health determinants that affect access and health engagement, as well as the risks of CVH: but with the overarching research objectives of this study across the health system that should be applicable to diverse migrant groups.

The research objectives of the thesis are as follows:

1. To explore the determinants of health across political and social frameworks, and the implication on CVH health engagement.
2. To explore the current role and effectiveness of CVH testing policy, within the context of national CVH policy initiatives in the UK; with the application of a policy analysis framework.
3. To identify the awareness, understanding and perception of liver disease and CVH in the newly arrived Nepali population, and the potential barriers or facilitators that may exist to CVH testing endeavours, and health engagement for testing.
4. To explore the awareness, practice and perception of CVH testing for migrant groups in primary care; contrasting these ideals with that seen in the local Nepali community
5. To develop a community based intervention to engage with and test members of the newly arrived Nepali population for CVH
6. To identify the principal gaps and levers for action to improve CVH testing delivery in the Nepali community and migrant groups in general.

Research Philosophy

Research philosophy considers how one views the world, and determines my research strategies, theory and analysis. Research philosophy considers both Ontological and Epistemological positions, with influence that these factors place on study design and discussion.

Ontology:

Ontology studies the nature of reality, and in particular it considers if reality exists entirely separate to human practices and interactions, or whether reality (including research) remains integrally linked to human practices and social interactions [Braun and Clarke, Chapter 2 2014, Saunders B 2009, chapter 4]. Ontological positions include Realism - where the natural and social world exists independent of human action, and where a single truth can be demonstrated through research techniques, and Relativism – where reality is considered in terms of multiple (possible) constructed social realities that differs across time and context, which therefore remains outside our ability to truly comprehend [Braun and Clarke, Chapter 2, 2014; Morgan ST]. In between these two approaches lies Critical Realism, where an interface exists between social interactions and realism, that helps to illuminate reality, even if it does not provide a fully reproducible measure of this (single truth) reality [Braun and Clarke, Chapter 2, 2014].

Given the relative extremes and limitations of realist and relativist based approaches, I adopt a critical realist approach during my thesis, including in my focus group studies, with outcomes that are viewed as socially influenced as well as determined by aspects of reality outside these social interactions [Braun V 2006].

Epistemology:

Epistemology is the study of “how we know what we know”, and considers the nature of knowledge, and what it is possible for us to know [Crotty M 1998, Chapter 1, Braun V Clarke 2013, Chapter 2]. Epistemology considers what one counts as legitimate knowledge, and how one views how meaningful (valid) knowledge can be created and obtained in the research process [Braun V 2013, Chapter 2]. Understanding one’s epistemological perspective is of crucial importance in the research process, and it can be visualised at the top of a hierarchical chain that informs the theoretical perspective and subsequent methodology and methods utilised to conduct the research project [Crotty M 1998, Chapter 1].

Epistemological positioning shapes how research is conducted and how conclusions are drawn, with many different philosophies that exist [Saunders B 2009, Chapter 4]. Commonly invoked positions include Positivism, with knowledge that is closely aligned to the natural sciences, and that is obtained through objective laws and generalisations, as well as Interpretivism, where knowledge is viewed

through our role and interactions as social actors in the research process [Saunders B 2009, Chapter 4; Braun V 2013]. Positivist approaches imply that the real world can be seen through objective measurements with hypothesis that can be drawn based on laws that can be proven, whilst interpretivist positions suggest that the world can only be inferred through our social interactions and own relations and role in society.

There are limitations to epistemological positions and in the relative extremes of a positivist or interpretivist approach. Positivism has received criticism for its exclusive focus on objectivity, and that only the observed phenomenon will lead to credible data, and a singular truth. As is to be expected, Interpretivism also receives criticism in the opposing lack of objectivity, and the reliance on social interactions that exclusively frame the knowledge one obtains, and how we make sense of the world [Saunders B 2009, Chapter 4; Braun V 2013].

The current study aims to understand the potential barriers and facilitators to viral hepatitis testing across multiple levels; exploring testing policy, as well as the awareness and perception of disease, and the ability to develop a successful engagement strategy in members of Nepali community. The epistemological position taken in this study is a Critical Realist approach, based on the work by Roy Bhaskar, developed in part to deal with the limitations posed by traditional epistemological approaches [Gorski P 2013]. Critical realism adopts the position that the objects, structures and practices that make up reality exist independently of whether their existence or nature is observable, known or understood by humans [Clark AM 2007]. Critical realism positions reality as existing beyond just observable phenomena, to include potential structures and powers that may actually, or potentially influence what is observed. It also acknowledges that different contextual factors may exist and interact to influence outcomes, including social, cultural and environmental factors. Critical realism aims to explain outcomes, taking account of these contextual factors that may, or may not be directly measurable, but causative and cumulative in certain circumstances and settings to produce the end outcome [Clark AM 2007, Gorski P 2013]. Critical realism considers a single reality, but provides a position to explore outcomes and the “truth” of relations through a rational basis, considering the multiple contextual factors, including cultural and social factors that are likely to be pivotal in analysing data in studies in migrant communities.

Theoretical Framework:

The theoretical framework provides structure and support for the foundations and rationale of the study, and provides a lens through which to visualise and analyse data [Reeves S 2008, Grant C 2015]. This framework is therefore crucial in informing methodology and the research process, and the

theoretical framework utilised of course reflects one's research philosophy as identified above [Grant C 2015].

In keeping with this, the theoretical framework utilised in this thesis is a Realist Evaluation framework, drawing upon the work of Pawson and Tilley, and built upon my critical realist epistemological positioning.

Realist Evaluation (RE) considers human action and outcomes within a stratified nature of social reality, with this stratified reality that considers all actions and outcomes within its broader social construct and meaning. It also considers outcomes and causal mechanisms as issues that are not fixed, but which develop in the context of the surrounding social structure, events and perception [Pawson R 1997].

RE looks to explore a particular programme activity to answer the question: "what works, for whom, in what circumstances and why" [Pawson R 2004]. In RE, programmes are explored to see how and why they work, with particular emphasis on the component actions and societal context that leads to success, or that may lead to failure in different circumstances, based on these components or contextual factors [Herepath A 2015, Jagosh J 2015].

RE therefore provides an explanatory approach that looks to generate causal associations that remains sensitive to contextual and social influences [Salter 2014], and considers both qualitative and quantitative data across multiple (micro, macro) levels within this social and contextual reality [Jagosh J 2015, Pawson R 2004].

RE is a middle-range theory that explores a programme activity, where the programme is considered as a sophisticated set of social interactions, grounded in a complex social reality [Pawson R 2004]. The programme is then explored to generate causal associations through the construction of a context, mechanism, outcome (CMO) configuration that is discussed below.

- Context considers the social, political, economic and other relationships that influence the aspects of "for whom" and "in what aspects" would a programme action be successful [Pawson R 2004]. These include the social and political factors that influence healthcare provision, as well as access and engagement factors to healthcare uptake.
- Mechanisms describe the aspect (action) of the programme that brings about its effects, including the perceived actions or inactions in the intervention that lead to success or failure [Herepath A 2015]. For a particular programme activity or goal, there may be different mechanisms, or ways through which the action achieves success or failure. Mechanisms consider not just individual component actions, but rather it explores the component, or components that works to produce change. The mechanism aspect therefore looks to identify

the crucial programme component/s that work to produce change, whether successful or unsuccessful [Pawson R 2004].

- Outcome: Outcome patterns consider the intentional and unintentional consequences of programmes, which may be successful or unsuccessful in their nature; relating to mechanisms that act under different contextual situations [Pawson R 2004, Salter K 2015].

This configuration can be applied to consider a whole programme intervention, or it may relate to a particular aspect of the programme. The CMO configuration is essentially heuristic, acting to provide a causative explanation about the outcomes seen from the observed data [Jagosh J 2015]. It provides a hypothesis that a particular programme outcome (O) is seen because of the specific action/actions seen in the mechanism (M), that is dependent upon the particular context (C) working at the time.

Realist Evaluation (RE) therefore provides an explanatory approach that looks to generate causal associations that remains sensitive to contextual and social influences, which is of key importance in the exploratory analysis of factors influencing viral hepatitis testing in migrant communities that will be heavily influenced by context, including political and societal factors.

Research Methods:

The thesis takes an exploratory approach to seek new insights into the potential barriers and facilitators to viral hepatitis testing in the UK Nepali community, as well as the burden of disease that exists in this new migrant community, through the establishment of a novel engagement strategy to reach out to this new population.

A mixed-methods approach is used to explore my research objectives, with an explanation of these approaches that is described in each intervention chapter. Qualitative strategies are used through policy analysis and focus group based studies in the Nepali community and with local General Practitioners (GPs), with quantitative data collection used to explore HBV and HCV risks in a defined population of the Nepali community through our testing intervention.

A summary of the principal research methods used in the thesis is presented below:

Policy Analysis:

CVH testing recommendations from NICE were analysed through a policy analysis framework, utilising the Policy Prioritisation framework developed by Shiffman and Smith, and validated by Walt and Gilson [Shiffman J 2007, Walt G 2014]. The framework looks to establish how policy can reach the political agenda, and its implementation into practice. Whilst initially applied in relation to global maternal mortality in low and middle income countries, the framework has received recognition

across many diverse health settings, including mental health [Tomlinson M 2012], as well as a heterogeneous exposure in the review by Walt and Galt, covering 22 policy papers, including health conditions such as family planning, HIV care, and HBV vaccination. [Walt G 2014]. Policy analysis is based on the context of the health system, and whilst the Policy Prioritisation framework has been principally applied in low to middle income settings, the research findings from this analysis should be transferrable; with recognition of the changing relationships and greater infrastructural support that should be available to developed health settings [Walt G 2008].

Qualitative studies:

Focus group studies were selected to explore the awareness, understanding and perception of CVH in the Nepali community, as well as qualitative studies in primary care. Members of the Nepali community were invited to participate with the help of Nepali community leaders, and identified in a purposive manner, given the new status of this migrant community. Nepali (bilingual) speaking moderators were used to run these focus group sessions.

Focus groups are a well utilised tool to explore knowledge and experience, and participants' points of view towards health and disease. They offer a way to expand the approach offered through semi-structured interviews to a wider group, with the group process that is thought to help participants "explore and clarify their views in a way that would be less accessible in one to one interviews", and may also provide a more in-depth view of interpersonal relations, and cultural perceptions that become apparent through verbal and non-verbal group interactions [Kitzinger J 1995]. There may also be advantages to using focus groups in potentially sensitive subject areas, and in communities where sensitivities to engagement may be considered; with focus groups well utilised in migrant communities [Greenwood N 2014]. Participants often feel more comfortable and expressive in homogenous groupings [Greenwood N 2014]., with focus group studies that were designed therefore to 4 separate discussions between older and younger Nepali male and female participants.

A Thematic Analysis (TA) approach, as developed by Braun and Clarke was used to analyse and identify patterns (themes) in the focus group data, providing a method to organise and interpret data expressed by participants [Braun V 2006]. This process relies upon "coding" to identify ideas expressed within the focus group text, and developing this through analysis to higher-level and overarching themes. Coding was undertaken by myself in all focus group work, with these codes generated in an inductive and iterative fashion, based on my research objectives, and with an aim to identify codes in a "latent (interpretative)" fashion; looking to identify patterns and meaning in the expressed focus group data [Braun V 2006]. High level codes, making up the candidate themes and overarching themes were then reviewed within the study group (consisting of the study supervisors, JH and SL).

A TA approach was chosen in addition due to its flexibility, [Braun V 2006] with language considerations in view of Nepalese medium focus groups that first required translation and then transcription, with the aim of identifying overarching themes (patterns) expressed by Nepali participants towards liver disease.

In our Primary Care qualitative studies, the same focus group methodology was used to collect data, with the aim for these focus groups to help identify perceptions and deeper feelings towards CVH testing in migrant communities. TA was similarly used for data analysis, with the aim of identifying qualitative data that could be compared between GPs and the newly arrived Nepali community who are served by them. GPs were also identified in a purposive manner, with dedicated study promotion to local practices and Clinical Commissioning Groups (CCGs).

Community-based testing intervention:

The UK Nepali community are a heterogeneous new migrant community with regard to ethnicity, caste and religion, with no understanding regarding methods that can be used to engage with this population, or how this would be received.

Given the uncertainties that exist in reaching out to this population, we developed a new Nepali research group, to work together to identify and develop locations and delivery models for CVH engagement.

A community-based testing intervention was developed utilising dry-blood spot testing for HBV and HCV. We promoted testing to members of the local community to test over 1000 Nepali participants, with the help of a dedicated research team, as well as the integral and vital support of Nepali community volunteers.

Quantitative research data was analysed through R-statistical software, as well as Microsoft Excel.

Rigor:

The rigor and quality of research can be considered with regard to the “authenticity” of the data, as well as the quality or “trustworthiness” of the data analysis [Sargeant J 2012].

To try and capture this authenticity and quality at the policy level, current NICE CVH testing policy was considered and analysed in the context of existing international and UK wide policy, with identification of the similarities and differences in policy at these levels.

For qualitative studies in the Nepali community, we developed focus group studies across 4 groups separated by sex and age, to improve our (purposive) study sampling and to explore perceptions across wider community representation. Nepali-speaking moderators were trained by study supervisors with qualitative study expertise (JH), and provided open-ended questions to explore

perceptions in the Nepali participants, as well as the broad subject of “liver disease” that was identified as the primary subject to avoid difficulties that may be faced with a specific lack of awareness of this term, and to explore broader aspects that may be at play.

Nepali transcripts were translated and transcribed by a single Nepali co-investigator (R Tiwari), with all initial coding undertaken by myself, with higher codes reviewed and modified through an iterative process within the research team (JH, SL).

Primary care focus group studies also relied on purposive sampling to recruit GPs, but were held in pre-arranged educational sessions, with a range of senior GP partners, salaried GPs and GP trainees in attendance from several regional practices. I acted as moderator in these sessions, with all participants aware of my clinical specialist role and current research objectives prior to the start of focus groups. Moderator questions were designed to be neutral, but focused to the research objectives of the study.

Initial coding was developed by myself, with the same Thematic Analysis process used for consistency, and with higher level codes and overarching themes that were reviewed and developed in the research team (JH, SL).

For our community testing study, a comprehensive multidisciplinary team was formed with the inclusion of Public Health, Local Council representatives, Patient liaison representatives, and a dedicated Nepali community research team, specially created for the study. Open-invitation to all adult groups in the Nepali community were promoted, with several testing sites in the local area developed to try and improve patient access. Quantitative statistical analysis was conducted with input from the Clinical Informatics Team at the University of Surrey, with the use of dedicated R-Studio software in logistic regression analysis.

Research Ethics

Formal national ethics application through the Health Research Authority was established for focus group testing studies in the Nepali community, as well as testing studies for CVH in the Nepali community. The study sponsor for this work was Frimley Park Hospital (Appendix)

Ethics approval for focus group studies in primary care was completed through the University of Surrey, without the (suggested) need for formal ethics approval given the nature of these focus groups, being conducted by myself as moderator in NHS to NHS staff sessions.

Ethics application for qualitative studies in the Nepali population, and developing a community testing intervention were submitted by one of the study supervisors Aftab Ala, with further ethics application for primary care qualitative studies submitted to the University of Surrey by myself.

Chapter Summary:

The current chapter presents an overview of the principal research objectives of the thesis, and the intervention strategies and analysis tools used to meet these objectives.

A Realist Evaluation (RE) framework is used as the theoretical framework in the design and interpretation of the study, with a mixed-methods approach that is used with the application of qualitative focus group studies using a Thematic Analysis approach, as well as a quantitative CVH testing study that is developed as part of a novel community-based testing intervention in the newly arrived Nepali community.

Chapter 3

*The role of CVH testing policy: Applying a Policy
Prioritisation framework to national CVH testing
recommendations*

Chapter 3: The role of CVH testing policy; applying a policy prioritisation framework to national CVH testing recommendations

Introduction:

This chapter explores the potential role of policy in CVH testing; looking at the historic context of policy development in the UK, as well as testing recommendations considered within an international context. A political prioritisation framework is utilised to analyse current NICE CVH testing guidance, and the potential barriers and facilitators that exist to achieving policy priority and uptake of CVH testing in migrant communities.

Context:

CVH testing in new migrant communities such as the Nepali population will be most influenced through policy that achieves wide uptake and implementation. Policy uptake is influenced by multiple factors, including the political, financial and environmental context, as well as the historic context of testing and how CVH is viewed between health professionals, the wider public, and migrant communities, who are one of the key groups targeted in CVH testing recommendations.

Policy is an initiative that can take shape in numerous forms, whether written (e.g. national guidelines) or unwritten, explicit or implicit, and provides a broad set of objectives to be achieved through the shared action of stakeholders (individuals / groups) at different hierarchical levels. Health policy can be viewed more specifically as those decisions, plans, actions (or inactions) that achieve a health objective within society [WHO Health Policy 2015].

Health policy can involve and affect all the institutions, organisations, services and funding arrangements in the healthcare system, as well as external voluntary, private and public organisations (such as patient charity groups) that influence the policy process (stakeholders) [Buse, Mays and Walt, 2005, pg.6]. Policies may be developed at the central (e.g. government) level, or equally they may be led and developed by practitioners (e.g. GPs/Nurses) or patient-advocacy groups [Erasmus E 2014].

The importance and need for effective health policy is to provide better outcomes for patients, or improved cost-effectiveness through well-structured guidelines [Eccles 2004]. Health policy provides a vision for a specific health objective, as well as short and medium term targets for care, and outlines the priorities and expected roles for stakeholders involved in the policy process [WHO Health Policy 2015].

Effective health policy is therefore fundamental towards achieving and standardising health objectives, and in building consensus amongst practitioners. However, the policy process is complex, and policy outputs may not match their intended outcomes, with deficits or barriers that may exist

across multiple levels; from initiation and agenda-setting, across policy formulation to actual implementation [Buse, Mays and Walt, 2005, pg 13; Berlan D et al. 2014].

In the case of viral hepatitis testing, several policy guidelines have been issued over the past ten years in the UK, with updated HBV and HCV testing guidance issued by the National Institute of Health and Care Excellence (NICE) in December 2012 [NICE PH43 2012].

These guidelines identify those individuals who should be offered HBV and HCV testing, and are applicable to all health professionals and workers associated with these at-risk groups. Such testing policy therefore affords the potential to improve, focus and standardise testing in all at-risk groups, including migrant communities who may otherwise be socially excluded, or be missed in ad-hoc testing patterns employed by heterogeneous health professionals.

National CVH testing policy has many advantages, but little is known about the awareness and uptake of this policy, with testing practice that is likely to be influenced by the historic and current context affecting CVH across multiple levels. Policy analysis offers a structured approach to understand the factors that influence and affect policy uptake, and that therefore affect the uptake of CVH testing in migrant communities, including the newly arrived Nepali population.

Research objectives:

The following chapter looks to explore the context leading up to the development of updated NICE CVH testing guidance issued in 2012/13, utilising a policy analysis framework to explore the factors that may influence the implementation and uptake of testing policy.

- To explore the international and national historic context of CVH testing policy
- To explore previous national CVH testing policy endeavours in the UK
- To explore the development of current NICE CVH testing policy, and its recommendations
- To conduct a policy analysis to understand the factors that may influence the uptake and implementation of testing policy in migrant communities
- To identify potential facilitators or barriers towards CVH testing policy uptake

Reflexivity:

As a working clinician, health policy documents are frequent across multiple specialities, and remaining abreast of these guidelines, and the priority that is afforded to policy reaching clinical consciousness is complex, and poorly appreciated in day to day practice.

Indeed I approached policy analysis with great interest, as a concept that is intuitive as well as complex, and greatly dependent upon the political, financial and public context, as well as the core message and certainty of the clinical message that policy puts forward.

Research Methods:

NICE HBV and HCV recommendations consider ways to improve awareness-raising in CVH as well as improving testing uptake, with the following analysis focused to explore and analysis NICE CVH testing recommendations in migrant groups. Community testing is the focus of NICE CVH testing recommendations, with primary care the principal and visible group in policy recommendations to consider and analyse at the ground (community) level directed to action testing policy.

A historic context was developed first on an international and national basis to help explore the development and potential impact of NICE CVH testing policy in relation to previous testing policy, and other international experiences of CVH testing.

A policy analysis framework was then chosen to explore the potential barriers and facilitators towards achieving effective policy uptake and implementation at the community level in migrant populations.

Policy Analysis: International and Historic context

International guidance on HBV & HCV testing:

Viral hepatitis is a global public health problem, and achieved WHO recognition in the 2010 World Health Assembly, with testing policy and management guidelines that have been issued by most developed nations [WHO 63.18].

NICE testing policy can therefore be viewed in regard to international policy, as well as within its historic context leading up to current guidance and practice.

Potential acquisition routes for HBV and HCV are well defined, and as previously discussed relate principally to contact exposure (familial, sexual), injecting drug use and iatrogenic transmission. Transmission and the risks of chronicity vary though between HBV and HCV, and all guideline documents present testing recommendations separately for HBV and HCV, although on a practical level these groups overlap, in keeping with common routes of acquisition amongst all blood borne viruses.

International testing practice varies widely based on country resources and government priorities, but globally the focus has generally been to adopt an at-risk testing strategy for HBV & HCV (case-finding); focusing on specific risk groups, rather than population based screening [Del-Poggio 2006].

International Testing Policy:

Testing recommendations in the USA are the exception to this, with the Centres for Disease Control (CDC) being the only advisory body to recommend HCV testing in all individuals born between 1945

and 1965; the so-called “baby-boomer” generation, introduced in 2012 [table 2a, 2b]. Over 75% of those identified with hepatitis C in the US originate from this generation, which may be due to a higher HCV prevalence during this period and/or to patterns of unsafe needle practices. Such policy has not been adopted in the UK, with a lower prevalence (<2%) rate cited in this age group [NICE 2012], and CDC guidance is therefore the first to recommend HCV testing across a defined age group [CDC, Why baby boomers should get tested].

Summary of CDC/AASLD recommendations for HBV testing

Recommendations for routine HBsAg testing in at-risk individuals, including:

- Persons born in regions of high and intermediate HBV endemicity (HBsAg 2%)
 - Including: Immigrants, refugees, asylum seekers, internationally adopted children
- US born persons not vaccinated as infants where parents (or one parent) were born in regions with intermediate (*)/high prevalence
- Injecting drug users
- Men who have sex with men (MSM)
- Immunosuppressed patients (chemotherapy, organ transplant)
- Elevated ALT / AST of unknown aetiology
- Donors of blood/plasma/organs/tissue/semen
- Haemodialysis patients
- All Pregnant women/Infants born to HBsAg mothers
- Household/Sexual contacts/needle-sharing of HBsAg persons
- Persons at risk of HBV exposure (needlestick/sexual assault)
- HIV positive persons

Taken from CDC: <http://www.cdc.gov/hepatitis/hbv/PDFs/ChronicHepBTestingFlwUp-BW.pdf> 2014

AASLD: <https://aasld.org/patients/Pages/ViralHepatitisPrevention.aspx#screening>

*AASLD guidance recommends testing all US born individuals with even one parent born in intermediate prevalence (>2%) HBV settings.

Summary of CDC/AASLD recommendations for HCV testing:

Persons who should be routinely tested for HCV based on their risk for infection include those who:

- Currently inject drugs
- Ever injected drugs, including those who injected once or a few times many years ago

Have certain medical conditions, including persons:

- who received clotting factor concentrates produced before 1987
- who were ever on long-term hemodialysis
- with persistently abnormal alanine aminotransferase levels (ALT)
- Were prior recipients of transfusions or organ transplants, including persons who:
 - were notified that they received blood from a donor who later tested positive for HCV infection
 - received a transfusion of blood, blood components or an organ transplant before July 1992/Clotting factor before 1987(*)
- All HIV-infected patients

Persons who should be tested once for HCV without prior risk factors include:

- Adults born during 1945 through 1965

Persons who should be tested routinely for HCV-infection based on a recognized exposure:

- Healthcare, emergency medical, and public safety workers after needle sticks, sharps, or mucosal exposures to HCV-positive blood
- Children born to HCV-positive women

Persons for Whom routine HCV testing is of Uncertain need:

- Recipients of transplanted tissue (e.g., corneal, musculoskeletal, skin, ova, sperm)
- Intranasal cocaine and other non-injecting illegal drug users
- Persons with a history of tattooing or body piercing
- Persons with a history of multiple sex partners or sexually transmitted diseases
- Long-term steady sex partners of HCV-positive persons

Centers for Disease Control and Prevention (CDC): Hepatitis C information for health professionals [<http://www.cdc.gov/hepatitis/hcv/guidelinesc.htm>]

AASLD recommendations: *AASLD recommends in addition the testing of those who received clotting factors before 1987

Table 2: CDC + AASLD guidelines for HBV & HCV testing

There are differences in CVH testing policy in migrant groups in US policy, and whilst US (CDC) recommendations identify HBV testing in migrant groups born in intermediate or high risk areas, there is no specific testing recommendations in migrant groups in the absence of additional risk factors, with a population birth-cohort method recommended for this group as well. The rationale for this variance is not explicit, and whilst there is recognition in AASLD guidance of the risks that migrant groups may

face with regard to HCV, it seems that this variance is driven by a lack of primary testing data in migrant communities in the host and native countries, as well as a reliance on the birth cohort system in the US system [CDC 2014, AASLD IDSA 2017].

CVH testing in migrant communities may take the form of testing through dedicated community-based interventions, or through health facility-based testing through primary or secondary care, or during the migrant entry process. Medical screening examinations for visa applications and new arrivals are an effective route to identifying and (potentially) treating medical conditions, including viral hepatitis at the point of arrival. However the visa-entry process often differs to internal health-testing policy, and in North America only refugees (including undocumented migrants) are assessed for viral hepatitis according to the above policy, but other immigrant (so-called “alien”) groups seeking visa, or permanent residency are not routinely approached for viral hepatitis testing [CDC 2012, Sharma 2015].

Similarly, medical-screening examinations (assessments) for entry to the UK, Canada and most European countries operate separately to internal health policy, and do not include routine viral hepatitis assessments, although some countries do employ a risk-assessment approach at the initial entry stage. Importantly though, the presence of viral hepatitis is not a barrier to country-entry [UK Visas and Immigration 2013, Sharma 2015].

UK and European context at the time of NICE policy development

There is wide variation across Europe both with regard to the prevalence of HBV and HCV, as well as the surveillance practices and testing strategies used. Certain elements of HBV & HCV testing, such as blood and organ screening is mandatory across the EU, but there are no pan-European guidelines on HBV and HCV testing. Nearly all countries screen pregnant women for HBV, or have routine neonatal vaccination strategies, and occupational risks are universally recognised. However there is wide variation in the testing strategies adopted for “at-risk” groups between countries, and the UK has only recently introduced universal vaccination for HBV at birth from 2017.

A summary of European testing and case-finding practice at time of NICE guideline development is presented in table 11, based on data presented in the Euro-hepatitis report 2012, as well as information from the European Centre for Disease Prevention and Control [ECDC 2010]. The testing practice presented for each country is a cumulative of national testing policy guidelines, as well as questionnaire surveys of clinical practice. This data was collected before the introduction of updated NICE guidance, and shows that the UK had few standardised-testing recommendations in place across Britain in comparison to other European nations, as well as a perceived lack of standardised clinical action on testing in many at-risk groups. Adding updated NICE testing recommendations to this table

does however highlight the potential impact of this policy; particularly with respect to migrant groups, who otherwise feature in a very limited context across much of Europe at this point [table 3].

	NETHERLAND													
	FRANCE		GERMANY		IRELAND		ITALY		S		UK		UK (NICE)	
Pregnant	B		B		B		B		B		B		B	
IVDU		C	B	C	B	C						C	B	C
Immigrants					B								B	C
GUM	B		B	C	B								B	C
Multiple Sexual Partner			B	C									B	C
Prison	B	C	B	C	B	C							B	C
Long-term healthcare					B								B	C
Occupational-exposure	B	C	B	C	B	C	B	C					B	C
MSM			B						B	C			B	(if HIV)

Table 3: HBV and HCV testing practice in European countries – UK data updated to represent 2012 NICE guideline [UK (NICE)]; Adapted from ECDC 2010 and Cebolla B 2012

According to the WHO Global Policy Report, close to 50% of countries across Europe had a national policy in place for testing and referral for HBV and HCV (table 5) [WHO Global Policy report 2012], with a further 66% of countries who had policy in place for the management (treatment) of CVH; with NICE issuing several technology appraisals over the past 15 years advocating the evolution of different treatment strategies for HBV and HCV. Importantly though, at a central governmental level, only France had provision of a designated Government body charged with oversight and monitoring of CVH services at this time [Table 4].

Country (Health expenditure %)	Written National Guideline HBV/HCV	Designate d Gov. Body oversight	Gov. Viral Hep B/C prevention and control policy	Chronic HBV / HCV monitoring	National Policy to prevent viral hepatitis in PWID	National HBV/HCV management guidelines	National Screening and Referral Guidelines
France (11.88%)	✓	✓	✓	CHB	✓	✓	✓
Germany (11.64%)	✗	✗	✗	CHCV	✗	✓	Only HCV
Ireland 9.19%	✗	✗	✓	✓	?	✗	✗
Italy 9.53%	✗	✗	✓	✗	✓	✗	✗
Netherlands 11.92%	✗	✗	✓	CHB	✓	✓	✓
UK 9.64%	✓	✗	✓	✓	✓	✓	✓

Table 4: Testing policy and government control of testing and management in Europe; countries are presented with their relative health expenditure as a measure of GDP (%);CHB = Chronic HBV, CHCV = Chronic HCV - adapted from WHO Global Policy Report 2013

Overall then, there is policy variation at the international level towards CVH testing, as well as variation in CVH care, with the UK felt to be performing poorly with regard to CVH care despite the existence of multiple policy documents. This fact was emphasised in the 2010 report by Sir Mike Richards, the (then) National Cancer Director, who identified the UK as coming 13th out of 14 developed countries in the appropriate use and provision of HCV drugs for eligible patients. In this report Italy and France (1st and 3rd places respectively) were in the top rankings, and looking at tables 3 and 4, these rankings would seem independent of policy content alone, and also independent of national healthcare expenditure [Richards M 2010].

Migrant testing policy is seen to vary significantly between countries, despite shared risks that many of these countries will face. As with US policy, the rationale for this is not explicit, but felt to represent gaps in data that exist regarding CVH risks from many countries in the world, who continue to suffer from structural resource constraints, as well as a lack of prevalence data on migrant groups in developed countries, with testing recommendations in these policy documents frequently qualified as “low quality evidence” accordingly [WHO February 2017].

The history of HBV & HCV testing policy and practice in England:

The Department of Health first recognised HBV and HCV as a priority following the report “Getting Ahead of the Curve” by the then Chief Medical Officer, Sir Liam Donaldson [DoH, Getting Ahead of the Curve 2002]. This report highlighted the growing burden of HBV and HCV infection, and the benefits

of treating these diseases early before complications develop. The report also demonstrated many of the risk factors for HBV and HCV that warrant viral testing, and the importance of HBV vaccination strategies in at risk groups.

Chronic HCV infection was highlighted as an important disease to tackle in this report, with the consequent publication of the HCV Strategy for England in 2002 [DoH, Hepatitis C Strategy 2002], outlining testing and management guidance for HCV, focusing principally on harm-reduction in those who use, or who are likely to inject drugs (namely injecting drug users, and the prison population in this report). Specific linked strategies were also recommended, including the formation of Managed-Clinical Networks: where GPs could refer suspected HCV cases into a central hepatology hub allocated to each region. A formal “Hepatitis C Action Plan” was published shortly after this in 2004, acting as a framework to institute earlier recommendations, and to highlight the importance of awareness-raising in the public and healthcare setting.

Best-practice guidelines on testing at-risk groups for HCV were also issued in 2004, aimed at GPs, Genito-Urinary clinics (GUM), Prison health workers and Drug and Alcohol teams to improve testing rates [DoH, Hepatitis C, Essential Information for professionals and guidance on testing, 2004]. These guidelines recommended offering HCV testing to all people if they had/were:

- Ever injected drugs/currently inject
- Received blood transfusion in UK before 1991, or blood products before 1986
- Recipient of organ/tissue transplant in the UK before 1992, or abroad in med/high-risk setting
- Children, if maternal HCV
- Regular sexual partner of HCV individual
- Exposed health-care worker
- Received medical/dental work abroad in risk-setting
- HIV positive individual
- Received tattoo or piercing in at-risk area/surroundings

DoH guidelines were coupled with promotional and educational material, with the provision of detailed HCV booklets, DVDs and Case-Examples to all General Practitioners following the 2004 HCV strategy (The DoH “FaCe it” campaign). However despite guideline development and educational endeavours, uptake and integration of guidance was perceived to be poor and variable across the UK. A study by D’Souza et al in 2004 following guideline and educational delivery showed varying levels of knowledge regarding HCV, with 14% of GPs incorrectly believing that an anti-HCV antibody result represented a cure, rather than potential acute infection from HCV. Further studies by the same group

identified a poor knowledge base in primary care regarding at-risk groups for testing and those who should be referred for treatment; a fact recognised in subsequent HCV-specific guidance issued by the RCGP (Royal College of General Practitioners) in 2007 [D'Souza 2004b; RCGP 2007]

Audit studies conducted by the APPHG (All Party Parliamentary Hepatology Group) amongst Primary Care Trusts (PCTs) in 2006 showed poor uptake and prioritisation of the HCV Action plan at the regional (community) level, with only 8% having reported enacting the plan, and over a third of PCTs nationally (36%) making little or no steps to implement the plans. Follow-up audits in 2008 showed improvement, but with still only 1/3rd of PCTs having managed to engage with the HCV Action Plan; leading to the APPHG's conclusions that HCV care was conducted in a "post-code lottery" system across the country [All –Party Parliamentary Hepatology Group, 2006; 2008].

HBV testing policy has historically focused on testing and vaccination strategies in certain high risk groups, with antenatal screening being the main policy focus (with high risks of vertical transmission for HBV, as well as available treatment options for pregnant HBV women). Many high risk groups were highlighted in the initial 2002 DoH report, but migrant groups were not highlighted as a specific risk group until subsequent reports in 2006 [HPA migrant health 2006], and only appear definitively in the latest 2012 NICE document. Universal HBV vaccination was only recently introduced in the UK in 2017.

Antenatal HBV screening has been in place in the UK since 2000 following a Department of Health directive, which standardised previously adhoc testing systems. Over time, and with the existence of HBV therapies that can be delivered during pregnancy, antenatal HBV testing has become culturally ingrained into health practice, but even in this well adopted testing system there are problems. Maternal testing results are typically relayed to the responsible midwifery team, who may or may not be based in primary care. Onward referrals are made during pregnancy by the obstetric team (or GP), with the focus primarily to prevent transmission to baby. Maternal treatment is generally only indicated if very high viral loads are detected, and for most mothers identified through this system, follow-up post-delivery relies upon continued patient engagement, with or without active GP engagement. Prior to the recent universal vaccination policy, vaccination rates to at-risk babies was known to be sub-optimal, with only 49% receiving a full course of injections [DoH 2011], and there is no organised strategy to identify or test the father / partner of an infected mother, which is reflected more globally across the health-system, with the lack of priority, oversight, coordination and integration of services that is required to fulfil the contact tracing (policy) requirements for CVH [Personal experience and reports – Surrey Pathology Service, 2015].

Testing in migrant communities

Prior to the development of NICE guidance, policy guidance from the DoH did not include specific CVH testing recommendations for migrant communities, but had listed support for chronic HBV testing in UK migrant communities presented in the 2006 HPA report into Migrant Health; based upon sentinel surveillance data and research studies. Likewise for HCV, testing recommendations in migrant communities arose later, and the UK were directed primarily towards the South Asian community, based upon information from HPA surveillance data, as well as research studies. The DoH acted in 2009 based upon these findings to issue a targeted awareness-raising campaign: “hepatitis C, the more you know the better”, with distribution among existing South Asian media and website platforms with advice-line support. It is interesting to note though that such formal advertising strategies or a combined approach was not used for HBV, despite similar uncertainties of existing numbers, and surveillance studies showing higher prevalence rates in migrant groups [NHS Choices 2009, HPA 2006]

Policy variation across the UK

Policy has not been designed or implemented universally across the UK. DoH guidance has been principally directed at England, with Scotland, Wales and to a lesser degree Northern Ireland adopting their own policy action plans.

The Scottish HCV action plan deserves mention within the UK picture, with a structured 2-phase approach that was introduced in 2006 and been widely lauded. The three main aims of the HCV Action Plan were to:

- Prevent the spread of HCV, particularly among IVDUs
- To increase diagnosis among those at-risk
- To ensure that those who are infected receive optimal treatment and support

Phase 1 of this plan (2006-08) was developed to identify the actual prevalence/burden of disease posed by HCV; the needs of these at-risk individuals, and the quality and quantity of existing HCV services. Phase 2 (2008-11) was developed based on these findings, and allocated a dedicated budget of £43.2 million, allocated to a total of 34 actions identified from phase 1 (over a 3 year period). Of this budget, £8 million was allocated to NHS boards for prevention, and £28.7 million allocated for testing, treating and support costs, with a further £6.5 million defined for national coordination and information generation.

Specific actions generated from this plan included the development of learning and support tools for the HCV workforce (including Scottish Intercollegiate Guidelines Network; SIGN recommendations), the formation of Managed Care Networks (MCNs) comprising healthcare specialists and relevant

stakeholders to provide coordinated and standardised care to patients, and the development of an organisational structure with accountability reporting from lead organisations to the central Scottish Government Public Health and Health Improvement Directorate (SGPHHID) (summarised in Fig 5) [HPS 2010].

Governance structure for Hepatitis C Action Plan Phase II

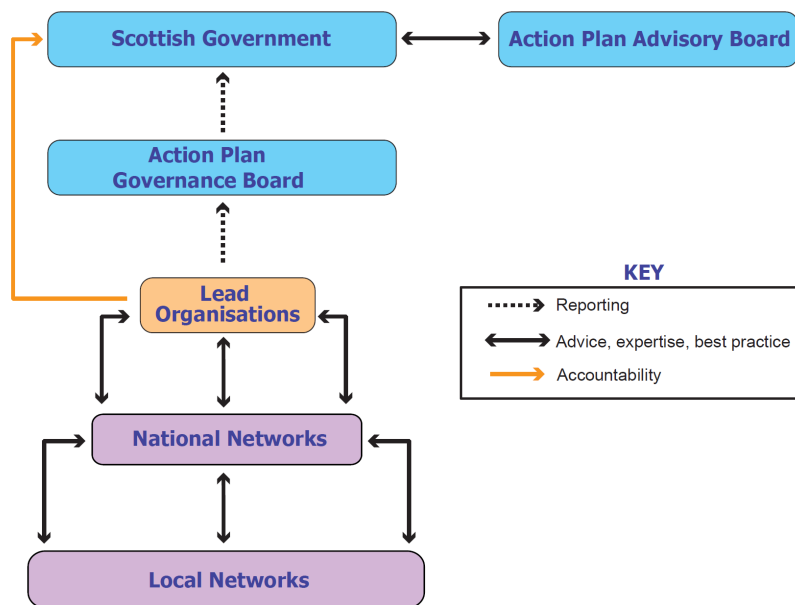


Figure 12: Governance structure for HCV detection and management in the Scottish HCV Action Plan, taken from Health Protection Scotland, HCV action plan, phase II 2009/10 [HPS 2010]

Since the introduction of the HCV action plan (phase II), the number of people initiated on therapy has increased from around 468 in 2007/08 to 1049 individuals in 2010/11 and has reportedly remained stable since. It is estimated that around 55% of HCV cases are now identified, and this represents an improvement from around 38% in 2006 before the start of the initiative. Patient groups, including the Hepatitis C trust have worked alongside government bodies to increase the awareness of HCV, including dedicated large-scale awareness-raising of HCV at the 2014 Commonwealth games [HPS weekly report 2014]. Since 2011 Scottish HCV care funding has continued alongside HBV and HIV care into an integrated sexual health and blood-borne viruses framework, with the continuing aims of providing an outcomes driven framework [HPS weekly report 2014]. This has the added advantage of pulling HBV care (and HIV) into an already successful model of HCV care].

A similar combined Blood borne viruses programme for HBV and HCV was also put into place in Wales in 2010 [Welsh Assembly Government, Blood Borne Viral Hepatitis Action Plan for Wales 2010-2015]. In Northern Ireland a HCV action plan was introduced in 2007, although there is no specific policy on HBV apart from vaccination strategies [Health, Social Services and Public Health, 2007]. As such there is wide variation in strategy and practice within the UK, and the Scottish strategy is highly praised for its structured and coordinated approach to disease assessment and management [Eurohepatitis 2012].

NICE hepatitis B and C testing guidelines:

The National Institute for Health and Care Excellence (NICE) produced new specific testing guidance for hepatitis B and C in December 2012 (updated with minor amendments in March 2013). This document: Ways to Promote and Offer Testing to People at Increased Risk of Infection; public health guidance 43, is unique in its focus being directed at the risk groups that should be identified and offered testing for HBV and HCV, and provides a basis for case-finding practice in the UK [NICE hepatitis B and C 2012]. This public health guidance is disseminated across the UK, but its focus is directed primarily at practice in England. Unlike technology appraisals public health guidance carries no mandatory requirements, but all NHS services, local authorities as well as the wider public (including voluntary and community services) in England are expected to take these guidelines into account in their practice [NICE and the NHS]. As such public health guidance aims to direct health policy through its listed recommendations.

NICE hepatitis B and C testing guidelines were developed following a request from the Department of Health with the stated aims:

“To produce programme guidance for commissioners and clinicians working in various settings on the most cost-effective methods for offering testing for hepatitis B and C to those at risk of infection” [NICE website:<http://www.NICE.org.uk/NICEmedia/live/11957/52314/52314.pdf>]

Guideline objectives:

The guideline aims are to increase testing uptake in at-risk groups and covers areas including:

- Awareness-raising in the general population & people at increased risk of infection
- Developing the knowledge and skills of healthcare workers and professionals who manage or interact with at-risk groups

- Testing-uptake in:
 - Primary Care
 - Prisons and Youth offender institutions
 - Immigration removal centres
 - Drug services
 - Genitourinary medicine (GUM) and Sexual health clinics
- Contact tracing of infected individuals
- Auditing and provision of neonatal HBV vaccination
- Commissioning HBV and HCV testing and treatment services
- Laboratory services for testing

Target groups

The guideline is aimed at multiple healthcare and non-healthcare groups that organise, co-ordinate and undertake testing, and those services that interact with at-risk patient groups. This includes:

- Commissioners and providers of public health services
- Hepatitis testing and treatment services
- Laboratory services
- NHS services / local authorities / prisons / immigration removal centres / drug services – that care for at-risk groups
- Voluntary sector groups that work with at-risk individuals.
- At-risk groups (e.g. migrant groups, injecting drug use and next-of-kin), or close-contacts

Guideline development:

Guidance was developed by the Programme Development Group (PDG) based on evidence from systematic reviews of study publications, as well as expert opinion. The document considered cost-effectiveness of interventions, as well as facilitators and barriers to testing uptake among at-risk groups. Draft guidelines were released for stakeholder and expert consultation in mid-2012, before being amended and finalised in December 2012 (minor amendments were subsequently made in March 2013).

Groups identified as at-risk for HBV and HCV

The risk groups identified at-risk for HBV and HCV testing in NICE guidance are similar to those previously described, but are far-reaching in many respects to prior DoH testing recommendations (Table 7 & 8). For Hepatitis B the specific risk groups identified in NICE guidelines are:

HBV: specific risk groups “Whose health will benefit?”
<ul style="list-style-type: none"> • People born or brought up in a country with an intermediate or high prevalence (2% or greater) of chronic hepatitis B. This includes <u>all countries</u> in: <ul style="list-style-type: none"> • Africa, Asia, the Caribbean, Central and South America, Eastern and Southern Europe, the Middle East and the Pacific islands • Babies born to mothers infected with hepatitis B • People who have ever injected drugs • Men who have sex with men • Anyone who has had unprotected sex, particularly: <ul style="list-style-type: none"> ○ <i>people who have had multiple sexual partners</i> ○ <i>people reporting unprotected sexual contact in areas of intermediate and high prevalence)</i> ○ <i>people presenting at sexual health and genitourinary medicine clinics</i> ○ <i>people diagnosed with a sexually transmitted disease</i> ○ <i>commercial sex worker</i> • Looked-after children and young people, including those living in care homes • Prisoners, including young offenders • Immigration detainees • Close contacts of someone known to be chronically infected with hepatitis B

Table 5: NICE risk groups for HBV; whose health will benefit [NICE 2012]

HCV: specific risk groups “Whose health will benefit?”
<ul style="list-style-type: none"> • People who have ever injected drugs. • People who received a blood transfusion before 1991 or blood products before 1986, when screening of blood donors for hepatitis C infection, or heat treatment for inactivation of viruses were introduced. • People born or brought up in a country with an intermediate or high prevalence (2% or greater) of chronic hepatitis C; this includes all countries in: <ul style="list-style-type: none"> ➔ Africa, Asia, the Caribbean, Central and South America, Eastern and Southern Europe, the Middle East and the Pacific islands. • Babies born to mothers infected with hepatitis C. • Prisoners, including young offenders. • Looked-after children and young people, including those living in care homes. • People living in hostels for the homeless or sleeping on the streets. • HIV-positive men who have sex with men. • Close contacts of someone known to be chronically infected with hepatitis C.

Table 6: NICE risk groups for HCV; whose health will benefit [NICE 2012]

The inclusion of testing recommendations in all individuals who have had unprotected intercourse, and the wide inclusion of testing in all migrant groups born or originating outside of Northern Europe and the US highlight how wide reaching these testing recommendations are, and the ambitious nature of these recommendations over previous national guidance.

Guideline Recommendations:

The NICE document identifies 11 recommendations based upon evidence presented in systematic review papers, as well as expert consensus opinion. The full recommendations provide a comprehensive list of testing recommendations that are aimed at all healthcare and allied professionals that interact with the diverse at risk groups who should be offered testing.

These recommendations cover awareness-raising, testing activity, contact tracing, as well as commissioning responsibilities. Some of the groups referenced are in prison and immigration centres, and GUM clinics, and the most relevant of NICE recommendations towards community migrant testing is presented in table 7 below:

<p>Recommendation 1: Awareness-raising in the general population</p> <p>This recommendation is to raise the profile of HBV and HCV in the general community; including the main routes of transmission, the asymptomatic nature of chronic infection and benefits of early diagnosis and treatment.</p>
<p>Recommendation 2: Awareness-raising for people at increased risk of HBV or HCV</p> <p>These aims are similar but targeted to at-risk groups, including those attending drug services, migrant community meetings or cultural sessions. Healthcare and community workers are advised to promote the importance of testing, the implications of having HBV and HCV and the benefits of early identification and treatment.</p> <p>In both recommendations the importance of overcoming the stigma surrounding HBV and HCV is emphasised, as well as the need to address material in a culturally appropriate manner. Many groups may also have difficulty with written material, and other methods of communication may also be needed. These recommendations are targeted at Government health departments, Local authority groups, Primary and Secondary care, GUM services and not-for-profit and non-governmental agencies.</p>
<p>Recommendation 3: Developing the knowledge and skills of healthcare professionals and others providing services to at-risk groups</p> <p>On-going education programmes are advised for doctors, nurses, allied-healthcare professionals as well as non-medical staff working with at-risk groups to increase adherence to guidelines, to improve testing uptake, and to improve the care and of established HBV and HCV individuals who may not be under appropriate follow up.</p>

These educational recommendations are aimed at the Royal colleges, Public Health England, Local authorities, local education centres and clinical commissioning groups.

Recommendation 4: Testing for Hepatitis B and C in primary care

This is aimed at General Practitioners and practice nurses, antenatal services and local community services that serve migrant groups. This recommends testing among at-risk groups that present to primary care/community services, and provides advice that includes:

- GPs and practice nurses should offer testing for adults and children at-risk for HBV/HCV, particularly in migrant groups from medium-, or high-prevalent countries, and in those with an injecting history (including performance enhancing drugs).
- Newly registered adults should be questioned about injecting drug use history.
- HBV testing and vaccination should be offered to men who have sex with men who are offered a HIV test (if no evidence of HBV immunity) (This relies upon co-existing NICE HIV testing guidance that recommends offering HIV testing to men who disclose that they have sex with other men, or if there is a large community of men who has sex with men, a high local HIV prevalence rate, or if requesting testing for other sexually transmitted infections [NICE, March 2011].
- HBV vaccination should be administered to all groups in primary care that are at-risk of on-going infection, and HCV testing should be offered annually to at-risk groups regardless of an initial negative test.
- All HBV or HCV diagnosed patients should be referred to speciality care
- Local community services working with migrant groups should work in partnership with primary care practitioners to promote HBV and HCV testing in adult and children at-risk groups. Awareness-raising should be a priority, with promotion of local health testing and treatment support.
- Antenatal staff at a hospital, community and primary care level should ask about risk factors for HCV during pregnancy, and offer testing to those with an increased risk.

Recommendation 10: Commissioning locally appropriate integrated services for hepatitis B and C testing and treatment

This covers the formation of a locally tailored service for HBV and HCV based on the underlying prevalence in each region. It recommends the addition of HBV and HCV into the health and wellbeing board's joint strategic needs assessment, which would involve CCG's monitoring absolute HBV and HCV numbers in each area, as well as predictions based on the prevalence of at-risk groups (including migrant and injecting users) to take account of those yet to be tested. Recommendations are also given for GPs to develop locally enhanced services with extra service provisions offered in areas of high HBV and HCV prevalence. Specific information is not given on how these services can be set-up, but the role of audit is emphasised to monitor the uptake of testing, referral and treatment success to ensure care plans are achieved. Recommendations are given for community services to be integrated with local specialist care to ensure there is a continuity between community testing services and treatment centres.

Table 7: NICE CVH testing recommendations (selected, in relation to community (documented) migrant testing)

Looking at these recommendations and the "at-risk" groups that they apply to, these recommendations seem far-reaching in comparison to previous national policy endeavours, and in comparison to international guidance issued at the same time. Testing in primary care is a key facet in these recommendations, with priority status in the potential provision of CVH testing to members of the newly arrived UK Nepali population.

The potential of this policy to facilitate and standardise testing, as well as linkage to care in migrant groups including the Nepali community therefore seems substantial and significant. However, the adoption and implementation of this policy is largely unknown, with real concern that NICE guidance may experience the same difficulties in uptake and understanding as previous DoH led guidance over the past 10 years [De Souza 2005, APPHG 2011].

The following section presents a policy analysis of these NICE testing recommendations, as an attempt to understand and demonstrate the potential facilitators and barriers that exist in achieving policy potential, and bringing NICE CVH testing recommendations into priority and focus.

Policy Analysis – Prioritising HBV and HCV testing policy

Policy analysis is a method to explore and explain aspects that influence the success and failure of policy. Analysis may look at the (written) content of policy alone, but more importantly policy analysis can be framed and focused to understand how Power and Process influences the policy process [Buse 2005].

Policy arises from a process of actions (or inactions) and relies upon a process of events for implementation. This policy process is complex and dynamic, with the Stages-Heuristic model one of the most widely used methods to consider this process in linear (simplified) component parts [Sabatier 2007, Buse 2005] (figure 13).

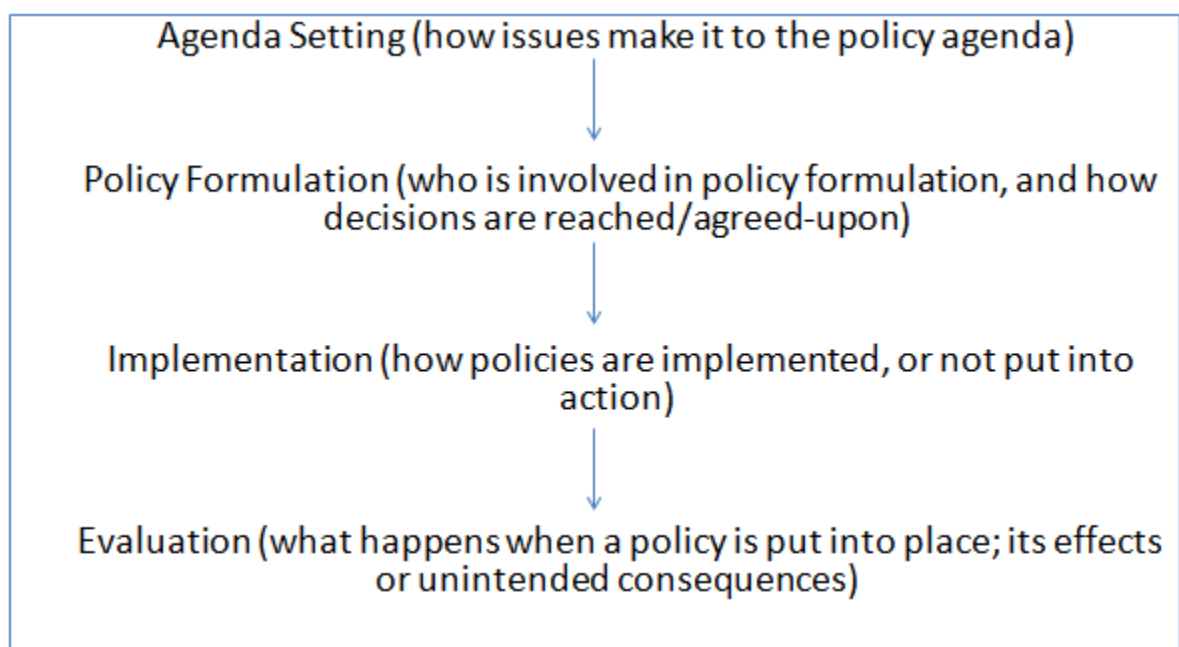


Figure 13: The Stages Heuristic model of the policy process – this policy process can be further considered as following a “rational-choice approach” – following top-down chain of command following shared objectives, or an “advocacy coalition framework” – with belief systems and affiliations between actors and institutions that influence objectives and policy activities [Sabatier 2007]

Policy analysis can therefore take many forms, framed to look at different parts of this policy process; considering the focus and impact of those who make decisions (Actors, and the Power they possess and utilise), as well as how decisions are made and implemented (Processes) [Buse 2005].

Well utilised policy analysis approaches include the broad-systematic Health Policy Triangle framework presented by Walt et al, looking at the role and relations between (central) actors, policy content, context and processes in how (and why) policy is (or is not) formed and implemented [Walt et al. 1994]. Policy analysis frameworks may explore theories of Top-down (rational) or Bottom-up (incremental) approaches to policy implementation, such as the use of Street-level Bureaucracy to explore the role and interaction of front-line staff in policy implementation [Buse 2005]. Other approaches may focus on the complex interactions between Actors across different healthcare settings (Actor Networks), such as the Advocacy Coalition framework; looking at how shared beliefs/values influence policy across multiple levels in the policy process [Sabatier 2007, Cerna L OECD 2013, Walt 2008].

Current NICE testing policy is far-reaching in comparison to historic testing recommendations, and international policy. However, as we have already seen, previous recommendations have received little priority, particularly in community (Primary) healthcare, where the burden of disease is the highest [APPHG 2008, 2011, D'Souza 2004]. It is important to therefore understand factors that influence the level of support that NICE policy receives, and how testing policy can be prioritised so as to increase testing opportunities in migrant communities.

The Policy Prioritisation Framework:

Analysing policy prioritisation looks at the barriers to achieving political attention and support, and the effect of this on policy goals. The framework presented by Schiffman and Smith, and further developed by Walt et al. provides such an analytical approach, with political priority defined as when: “political leaders consider an issue to be worthy of sustained attention and will back up that attention with the provision of financial, human, and technical resources commensurate with the severity of the problem” [Schiffman et al. 2007]. Schiffman further describes this state as being met when 3 conditions are achieved [Schiffman 2007, Tomlinson 2012]:

1. National political leaders publicly and privately express sustained concern for the issue
2. The government enacts policies to address the issue
3. Resources (appropriate to the disease burden) are allocated and released

The following discussion will use this framework to analyse the level of prioritisation that is seen, or could be expected to be achieved with current NICE testing policy. Policy prioritisation can be

visualised as part of the “agenda-setting” process in the stages-heuristic model, and therefore whilst it does not focus on all aspects of the policy process (including implementation); achieving this political priority is of crucial importance to NICE testing policy, and in improving the uptake of viral hepatitis testing in migrant groups.

The original framework presented by Schiffman and Smith include 11 determinant of political priority grouped into 4 categories: Actor Power, Ideas, Political Context and Issue Characteristics. Although initially applied to the international stage, the framework has also been utilised on the national health policy stage [Walt 2014, Tomlinson 2012]. This framework was further adapted in a review conducted by Walt et al, with the addition of an “Outcome” category to the original framework [Walt 2014].

Support (prioritisation) is more likely to be achieved if specific objectives are met across each of the framework components, with a summary of this adapted framework presented in figure 14.

	DESCRIPTION	FACTORS SHAPING POLITICAL PRIORITY
ACTOR POWER	Strength of individuals / organisations	<ul style="list-style-type: none"> • Policy community cohesion • Unifying Leadership (Champions) • Guiding organisations • Grassroots mobilisation
IDEAS	How the issue is understood and portrayed	<ul style="list-style-type: none"> • <i>Internal frame</i>: policy community agreement on the definition of, causes-of & solution to the issue • <i>External frame</i>: Public portrayal of issue, and how this resonates with external agencies/government
POLITICAL CONTEXT	The environments in which actors operate	<ul style="list-style-type: none"> • <i>Policy windows</i>: political moments/events that present opportunities for action • <i>Governance structure</i>: how institutions /bodies work together to achieve goals
ISSUE CHARACTERISTICS	Features of the problem	<ul style="list-style-type: none"> • <i>Indicators</i>: having clear measures to show severity of issue and to monitor progress • <i>Severity of issue</i>: as measured by objective measures • <i>Effective interventions</i>: cost-effective / validated / simple interventions
OUTCOME	The resources allocated to policy	<ul style="list-style-type: none"> • Whether the issue was being taken seriously by policymakers , represented by: Resource allocation / Authoritative decisions

Figure 14: The political priority framework, adapted with input from Walt and Gilson [Shiffman et al. 2007, Walt 2014]

The following discussion utilises this framework to analyse the support that is seen, or could be seen for NICE viral hepatitis testing policy in migrant communities.

Actor Power:

The actors (stakeholders) involved in health policy consider the individuals, groups and organisations that affect health policy. This may include members of (central and local) government, policy advisors, healthcare professionals, and patient and charity groups. Most actors cause effect as part of a group or organisation, and their role or action typically reflects the standing (power) of the group to promote or attenuate policy outcomes [Buse 2005].

Actors may affect policy through its promotion, but equally may act to limit or hinder policy development and adoption. The power or ability of each group to effect policy is a measure of its influence to exert outcome, and this “power” can be thought of as the political resources available to the group/individual; whether or not this power is real or perceived. Political resources may be a measure of social standing, wealth, job or official position, as well as the level of access to knowledge in a particular field that facilitates an authoritative status [Buse 2005].

The role and position of Actors is therefore crucial in the policy process, from initiation to implementation and reform; with successful initiatives known to differ based on the strength of those who participate in them, as well as the quality of linkages between these actors in their collective efforts [Shiffman et al . 2007].

Actors in the CVH testing policy process:

The actors involved in CVH testing and care include Government and departmental agencies (NHS England), Local Authorities, PHE, CCGs, Primary Care and other community health organisations, as well as patient advocacy groups and pharmaceutical agencies. These actors can occupy positions that are unique or multiple across the macro, meso and micro levels linked towards policy and its action; in this case with the micro-level delivery of CVH testing at the community level.

The priority-setting framework identified by Shiffman and Smith considers Actor Power as a measure of Community Cohesion, Strength and Leadership, the Effectiveness of organisations, as well as the Mobilisation of civil-society and grass-roots organisations in achieving policy objectives (figure 14).

The commissioning responsibilities of the principal stakeholders in CVH testing and management is presented in fig 15.. Commissioning is the process of planning, purchasing and monitoring services [Kings Fund Clinical Commissioning], with commissioning responsibilities for CVH testing that lies between NHS England, Local Authorities, PHE and CCGs. In CVH care, NHS England commissions services for testing activity in primary care, with Local Authorities responsible for commissioning

activity that takes place in drug and alcohol centres, or sexual health/GUM clinics. Specialist referral to secondary care, and monitoring activity in clinics is commissioned by CCGs, and CCGs are also responsible for commissioning services for those individuals who develop end stage complications of cirrhosis, including HCC and transplantation (with the exception of drug costs) [HCV Action 2016]. CCGs are also tasked with the development of established referral networks to secondary care, which may then be used by Local Authority agencies if required under other community based testing initiatives. Antenatal testing as part of the Infectious diseases in pregnancy screening programme falls under the commissioning responsibilities of NHS England area teams, as well as CCG linked antenatal teams [NICE 2014]. Importantly, recent specialist commissioning arrangements taken by NHS England have led to the centralised commissioning of CVH treatments [NHS England September 2017], reducing the burden on CCGs, and driving the establishment and legitimacy of Operational Delivery Networks (ODNs); created in the UK to deliver high cost CVH drugs in expert central (hub) centres, to other peripheral (spoke) hospitals [NHS England July 2017] (figure 15).

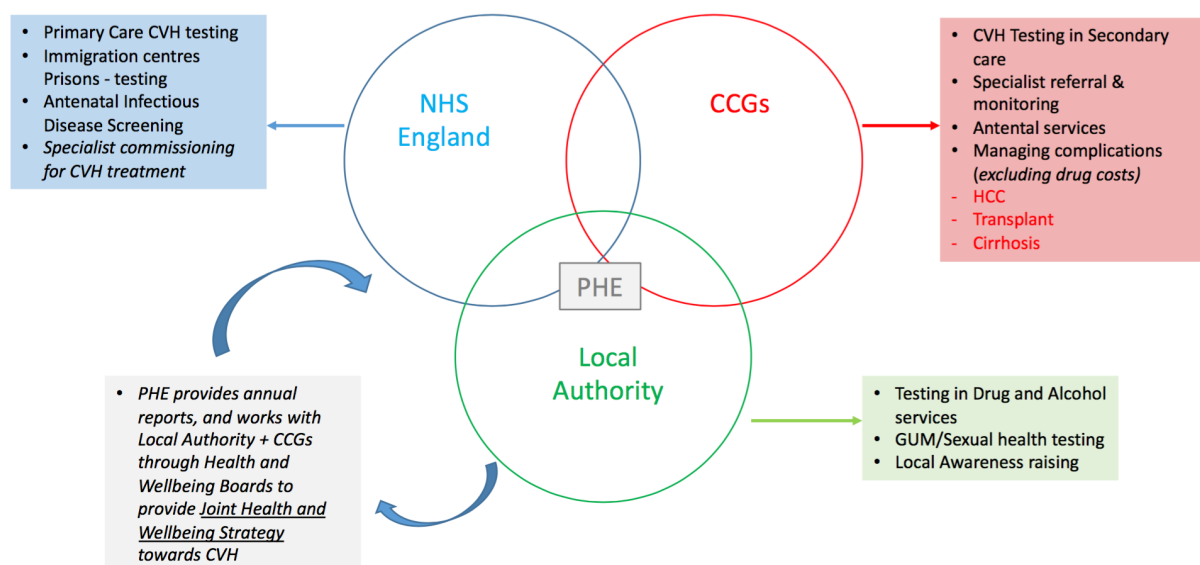
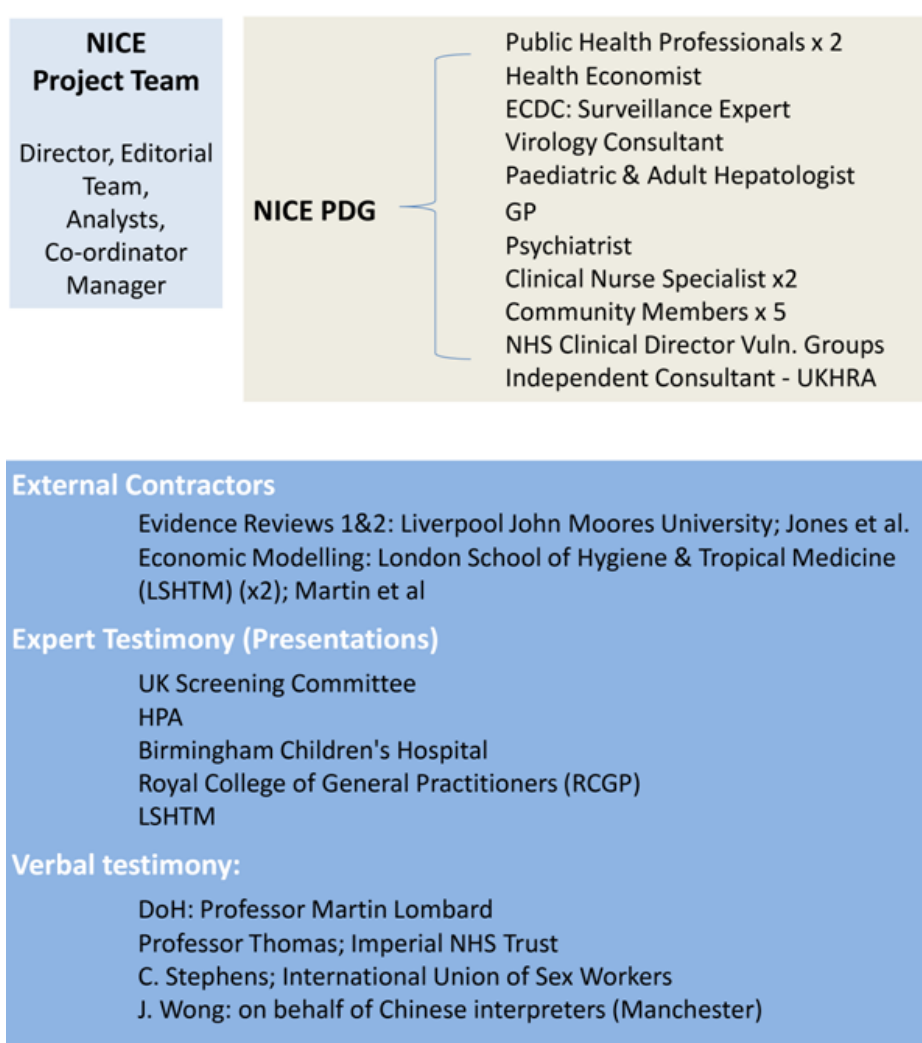


Figure 15: : The commissioning relationship & responsibilities for NHS England, CCGs (Clinical Commissioning Groups) and Local Authorities in the testing and management of CVH. PHE (Public Health England) plays a role at all levels, as well as its role in the Health and Wellbeing Boards in monitoring and providing feedback on local CVH needs in the population (adapted from NHS England HIV services 2015)

Policy Community Cohesion:

“A policy community that agrees on how the problem should be solved are more likely to acquire political support” [Shiffman J 2007].

Cohesion in the Policy development process: Looking at the CVH policy development process, it can be seen that this follows largely a “top-down” approach [Buse K 2005], with little direct involvement of primary care or representatives from the (then) Primary Care Trusts (PCTs). A representation of this programme development group (PDG) is demonstrated in figure x, with the PDG receiving evidence from 2 systematic public health reviews, 1 economic modelling study [Jones a, 2012; Jones b, 2012; Martin 2013], as well as oral testimonies from health experts (including 1 GP) and members from potentially at-risk communities (the International Union of Sex Workers, and a presentation on behalf of Chinese interpreters) (figure 16, table 8).



PDG = Programme Development Group, ECDC = European Centre for Disease prevention and Control; UKHRA = UK Harm Reduction Alliance

Figure 16: : NICE guideline stakeholders

Presentation	Content	Position
UK National Screening Council (UKNSC)	Difference between Case-finding and Screening	Unclear: Previous publications [Allaby M 2010] did not recommend a screening programme for Hepatitis B & C among ethnic minorities
HPA	Selective vaccination of high-risk groups is not cost-effective There are gaps in the knowledge of viral hepatitis; with regard to epidemiology and progression (cirrhosis rates are higher in Taiwan vs USA for HBV)	Supportive
Ministry of Justice	High rates of HCV in prisons (14.7%), second only to PWID. HBV vaccination and HCV treatment aims presented.	Supportive
Birmingham Hospitals Children's Services	Overall limited data on paediatric HBV and HCV. Role of testing new immigrant families and asylum seekers presented, but again limited data sets. Benefit of early harm-reduction strategies, including in care-homes. Role of GPs and Community centres in reaching at-risk groups presented	Supportive
Primary Care Physician <i>(GP with Special Interest in Substance Abuse; Royal College of General Practitioners)</i>	There is a knowledge gap in primary care relating to viral hepatitis, with accompanying fear. Lack of prioritisation concerning viral hepatitis, and the role of case-finding in primary care. Recommends the development of clear concise guidelines for GP to improve testing practice	Supportive
LSHTM (Public Health)	The role and benefit of testing for viral hepatitis in Drug and Addiction Services	Supportive

Table 8: Summary of expert testimony presentations to the NICE PDG (Programme Development Group) with the inferred position statement of each group; PWID = People who inject drugs, LSHTM = London School of Hygiene and Tropical Medicine

Overall, the position of these evidence pieces is supportive towards improved CVH testing initiatives, and whilst there are uncertainties that are discussed regarding the understanding of underlying CVH risks, there is broad consensus to improve CVH testing initiatives, and this is represented in the policy wording. The position taken by the UK National Screening Council (UKNSC) is somewhat unclear, and previous screening estimates in 2010 identified numerous gaps in the attempted implementation of

such policy (although screening, over case-finding), and it is likely that the PDG would have been aware of these previous suggestions [Allaby 2010].

Policy cohesion in principal stakeholders: The actor network involved with CVH case-finding activity is complex, with a summary of these relations that is presented in figure 17. Case-finding activity and testing in migrant groups is delivered at the micro-level, with primary care testing activity that is likely to be the most effective route of intervention on a wide scale.

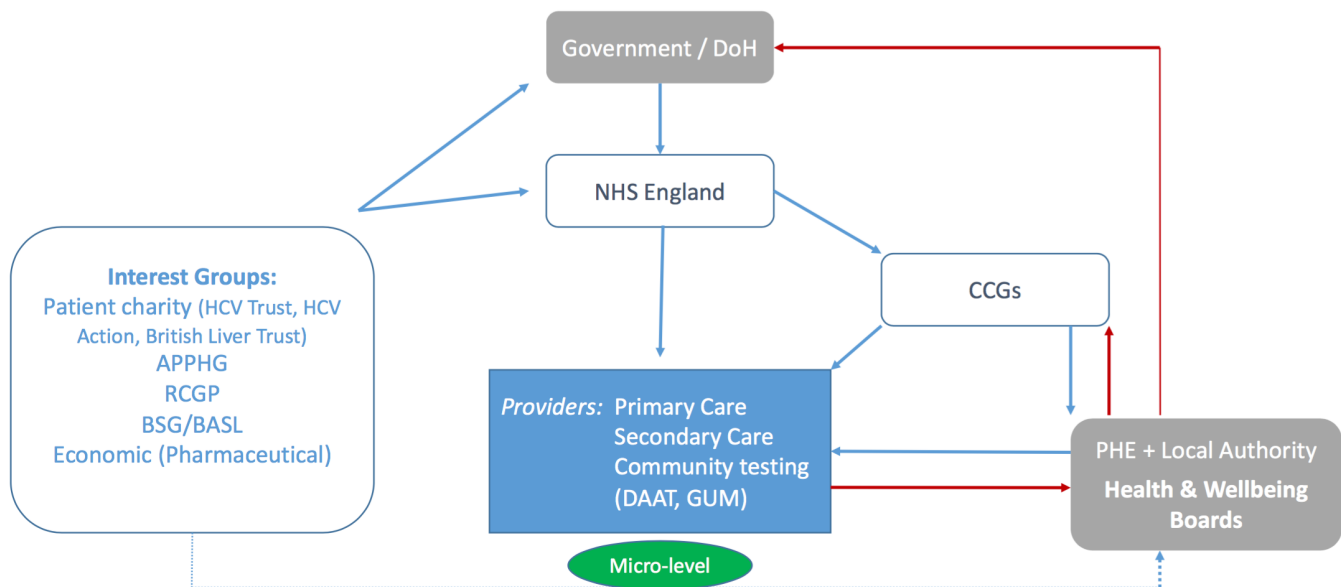


Figure 17: A network map of relations between the principal Actors involved in community CVH testing and onward care. Red-lines indicate the feedback loops that should be in place to report and monitor CVH rates as part of the Joint Health and Wellbeing Strategy.

At the central government level, senior (executive) politicians have expressed support for liver disease and HCV in particular, with the Prime Minister David Cameron expressing his support whilst in opposition and in government; including his statement issued on World Hepatitis day in 2012 highlighting the need to improve testing for HCV [Hep C trust website March 2013]:

“With more people being tested for hepatitis C, and treatments improving all the time, an early diagnosis can make a real difference. But it's critical that people who could be at risk continue to be tested, as it's a disease which can go undetected for years. We are looking at how we can strengthen efforts to prevent and control hepatitis C in the future, as part of our strategy for combating liver disease. But today, on World Hepatitis Day, I urge everyone who could be at risk to go and get checked out.”

Support for CVH testing policy would also seem evident at the government departmental level, with the DoH (Department of Health) having issued high level policy documents to advocate for CVH testing for over 10 years, including specific targeted interventions to improve and explore CVH testing in the

South Asian community [Hepatitis C; the more you know, the better, 2009]. The Chief Medical Officer (CMO) has been likewise consistent in raising the profile of CVH in reports to the DoH, including the 2012 “On the State of the Public Health” report, which highlighted the growing burden of morbidity and mortality from liver diseases in the UK over other developed European nations, and identifying CVH as one of the 3 leading causes for this [Davies 2012].

Criticisms have been made against the omission of liver diseases within the original 195 Quality Improvement Indicators set by NHS England; but on the positive side the government has shown commitment towards liver disease with the inclusion of liver disease in domain 1 of the NHS Outcomes Framework, and domain 4 of the Public Health Outcomes Framework; with HCV identified in draft NHS England consultation documents as the “cause of liver disease most amenable to healthcare intervention” [Williams R 2014, Heath and Social Care website, DoH Nov 2013, NHS England HCV network 2015].

More recently NHS England has led the way with support for national commissioning of HCV treatments through the Early Access Scheme in the UK, and with the development of ODN models to procure and deliver new DAA therapy to nearly all patient groups, supported by positive appraisal recommendations by NICE [NHS Clinical Commissioning 2015], and overall senior government level support appears evident in improving CVH case-finding initiatives, albeit in the context of resource constraints and the difficulties faced by the radical overhaul of the Health and Social Care Act that are discussed in later sections.

PHE occupies now a role at the local and national level, fulfilling a meso-level function in health monitoring and advocacy following the Health and Social Care reforms. PHE, and the previous HPA representatives have demonstrated support for CVH testing initiatives, and in the recent goals of CVH eradication. However, the newly formed PHE has received criticism for role and independence as a public health champion, and therefore in the direction and power it now yields [House of Commons Health Committee, Feb 2014].

At the local and regional level, the support and cohesiveness of this support is more difficult to ascertain. In primary care, previous CVH policy endeavours were met with low levels of awareness and confidence in managing CVH [D’Souza 2004, RCGP 2007], with these concerns raised again in the expert presentations made to the NICE PDG [NICE 2012].

Support is evident at the level of the RCGP (Royal College of General Practitioners), with interim CVH guidelines released in 2007, and educational tools issued to all practitioners following the release of current NICE guidance; with around 1380 individuals who had completed the e-module by late 2013,

and around 710 individuals who had attended face to face sessions arranged by the RCGP [PHE HCV 2014, RCGP 2007]. Findings from PHE suggest that these educational interventions may have led to an improvement in HCV testing rates, although the perception of primary care physicians to testing, and updated NICE CVH testing guidance is essentially unknown [PHE HCV 2014].

CCG level support towards CVH testing policy is also difficult to interpret, with few studies in this area, and with 211 (largely) independent CCGs set up as part of the Health and Social Care Act. Recent audit studies by the Hepatitis C Trust would though do suggest ongoing deficits in the priority afforded to HCV [Hepatitis C Trust, Feb 2013; Kingston CCG July 2015, Warwickshire CCG website], and a reduced cohesion in policy support overall for CVH testing that appears evident at the micro-level, where testing activity should be delivered.

Similar concerns can also be seen at the Local Authority level, with a low priority that CVH receives at Health and Wellbeing Boards, where CVH rates should otherwise be monitored and coordinated at a regional level through the formulation of Joint Health and Wellbeing Strategies [HCV Action 2014].

Overall then, there is an apparent loss of support and policy cohesion that is seen in moving from the top-down actors involved in championing and supporting policy development, and the local regional meso and micro-level actors involved with facilitating testing at the community level, that may impact migrant testing.

Leadership:

Looking back at the network map of actor relations in CVH (figure 15), it can be seen that there is no formal body charged with providing oversight or coordination for testing services between NHS England and micro-level interventions in primary care.

A National Liver Disease Strategy was one of the election pledges of David Cameron's Coalition government, with the recruitment and appointment of a national clinical director for liver diseases in 2010 before the strategy was abandoned in 2013 without replacement, with the Health and Social Care Act likely to have played a significant part in the abandonment of a senior level political commitment [Parliamentary Reports Nov 2013].

Looking at the local and regional level, Health and Wellbeing Boards were established as part of the same Health and Social Care Act, with the responsibility to understand the health needs of the local population, and to develop strategic vision to commission and monitor services according to local needs. Accordingly, these Health and Wellbeing Boards should develop Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWS) that takes account of CVH risks, and the management needs. The Health and Wellbeing Boards are a combined measure of Local

Authority representatives, CCG representatives, as well as PHE, and appear attractive in their potential to offer leadership to CVH testing in migrant communities.

However, whilst the Health and Wellbeing Boards have a statutory duty along with CCGs to produce these strategic needs assessments, it is left to these boards to prioritise their own direction [DoH 2011] and data from the HCV Action charity identified that even in high prevalence Health and Wellbeing Board regions, only 3 out of 10 had developed a health needs assessment for HCV, with additional formal criticism raised in the House of Commons over its inability to follow commission direction [HCV Action 2014, House of Commons Report 2013].

Liver disease also falls under the targets of Local Authorities as part of the NHS Public Outcomes Framework [Social Policy Section 2014]. The introduction of this framework has meant that local authorities now record specific information on mortality rates related to liver disease, and as seen in the resulting data sets drawn across the UK (figure 18), associations can be drawn between liver disease and markers of social deprivation, with additional concerns for newly arriving migrant communities, who may face social deprivation themselves on arrival to the host country. Aldershot is the main location of later testing work, and despite the relative affluence seen in Hampshire, there is heterogeneity and areas of deprivation, with two areas in Aldershot that fall within the 20% most deprived in the UK based on local authority deprivation scores (figure 18)[Rushmoor council 2015].

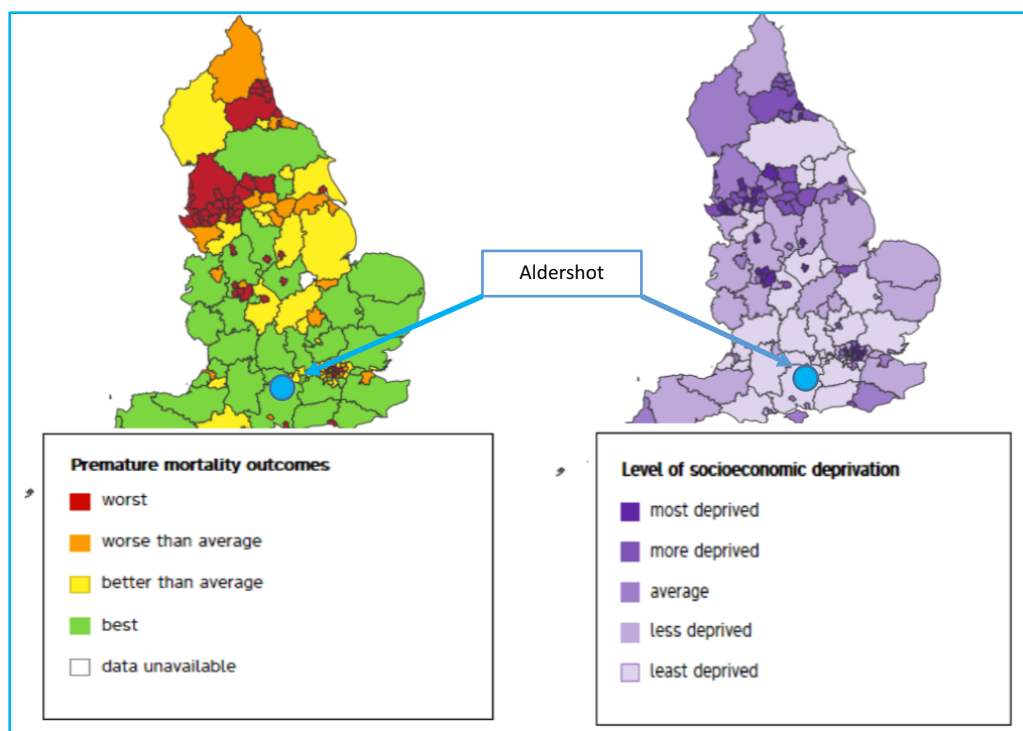


Figure 18: Liver disease mortality and socioeconomic deprivation - adapted from Public Health England (Public Health Outcomes Frameworks) <http://longerlives.phe.org.uk/>. Aldershot is identified within Hampshire

The involvement of Local Authorities in this monitoring activity may provide an additional role and motivation for improved engagement in CVH monitoring at the Local Authority level, which can then be filtered into the Joint and Health Wellbeing structure with the aim of improved local leadership in CVH testing activity.

PHE also demonstrates potential in its ability to lead and champion CVH testing policy, with its action across multiple levels in the new NHS structure, and given that CVH fits well into the ideology and context of PHE objectives. However, this too has come under criticisms in its leadership capacity, with formal rebukes delivered at the House of Commons Health Committee, with concerns raised over its independence from government, as well as criticisms over health inequalities demonstrated across London as a lack of oversight and control by local PHE in identifying and targeting these factors [House of Commons Health Committee, Feb 2014, Guardian January 2014].

At a regional level, the recent creation of Operational Delivery Networks (ODNs); created as by-product of commissioning guidance issued by NHS England to control and facilitate the standardised delivery of high-cost HCV (DAA) treatments, may serve a leadership role for the wider community. By standardising the referral and care pathway for patients diagnosed with HCV (through designated hospital multidisciplinary settings), this system should improve the awareness and confidence of local practitioners toward diagnosing and managing CVH patients, and may filter through local commissioning services to facilitate testing offers to other at-risk groups. Given the very high rates of success for newer HCV treatments, this system should facilitate confidence in testing in the longer term. Whilst, these systems were developed as “hospital-centric” organisations made up of hepatology specialists, they have evolved over time and drawn CQUIN (Commissioning for Quality and Innovation) funding and a lauded status. Recent publications suggest that as the current number of “known” HCV patients are exhausted, the attention of this body will evolve and turn towards case-finding, with a potentially very attractive (and funded) specialist team who can help provide leadership and coordination to CVH testing.

Overall, leadership at the local and regional level through the established structures of the Health and Social Care Act seem limited in their ability to provide clear leadership and coordination to CVH testing, but with the potential for the newly formed ODNs to act in a leadership and coordination role in CVH testing activity.

Guiding Organisations:

The speciality societies in Hepatology across Europe and the UK have provided guidance primarily on treatment strategies for those known to be effected by CVH, and may not be well accessed by non-specialists, including those in primary care.

One of the most ambitious and inclusive framework to target liver disease is that put forward in the Lancet commissioned, led by Roger Williams. It draws together collaboration from the principal UK charity groups (British Liver Trust, Hepatitis C Trust and The Foundation for Liver Research), as well as the medical society groups, including the RCGP [Williams 2014].

The original commission provided a clear evidence base to highlight the growing burden of liver disease in the UK compared to other European nations, and presented 10 key evidence-based targets for intervention (figure 19).

Summary of the ten recommendations in the 2014 Lancet Commission on Liver Diseases	
1.	Strengthen the detection of early liver disease and its treatment in primary care
2.	Improvement of support services in the community for screening people at risk
3.	A blueprint for improving care for acutely sick patients through establishment of liver units in district general hospitals and regional specialist centres
4.	A national review of liver transplantation services in the UK
5.	Strengthening the continuity of transitional care from child to adult services
6.	Scaling up of national action to reduce the country's overall consumption of alcohol
7.	Promotion of health lifestyles to address the current epidemic of obesity
8.	Eradication of hepatitis B and C virus infections by 2030
9.	Greater provision of medical training in hepatology and wider opportunities for all health professionals to increase knowledge of liver diseases
10.	Launch of a national campaign to increase awareness of liver disease in the general population

Figure 19: Summary of the 10 recommendations from the initial 2014 Lancet Commission [Williams 2014]

Whilst the commission targets all aspects of liver disease, including the need for Minimum Unit Pricing for alcohol and controls for obesity, it draws special attention to the need to target liver disease in at-risk groups in the community through improved awareness raising and resources, and places a set

target to eradicate HBV and HCV by 2030; based upon the efficacy predictive benefits of new HCV therapies, as well as universal vaccination and appropriate treatment for HBV. The commission identifies the need to offer testing to migrant communities, as well as the uncertainties that exist in how best to reach these communities.

The 2030 target has been further adopted in the WHO report in response to the World Health Assembly request, and whilst the target for intervention is aimed principally at low and middle income countries, it provides clear vision and justification that effective control of CVH is achievable on a global scale with 5 practical steps; with an upscaling in CVH testing to diagnose 90% of all cases by 2030 (table 9) [WHO 2016].

Target areas		Baseline 2015	2020 target	2030 target
Service coverage	Prevention	① Three-dose hepatitis B vaccine for infants (coverage %)	82%	90%
		② Prevention of mother-to-child transmission of HBV: hepatitis B birth-dose vaccination or other approaches (coverage %)	38%	50%
		③ Blood and injection safety (coverage %)	Blood safety: donations screened with quality assurance	95%
			Injection safety: use of engineered devices	100%
		④ Harm reduction (sterile syringe/needle set distributed per person per year for people who inject drugs [PWID])	20	200
	⑤ Treatment	5a. Diagnosis of HBV and HCV (coverage %)	<5%	30%
Impact leading to elimination		5b. Treatment of HBV and HCV (coverage %)	<1%	5 million (HBV) 3 million (HCV)
	Incidence of chronic HBV and HCV infections		6–10 million	30% reduction
	Mortality from chronic HBV and HCV infections		1.46 million	10% reduction

Table 9: The 5 key targets to achieve as part of WHO modelling to achieve control of CVH worldwide by 2030 [WHO 2016].

The Lancet commission group released a further update in 2015 highlighting the challenges that exist in translating guidance into practice at the community level, and proposing a bid through the RCGP to make liver diseases a priority through a Clinical Priorities Programme [Williams 2015].

The strength of the commission lays in its inclusiveness of the major patient advocacy (grass-root) groups, and attempts to unify specialist clinicians and primary care groups, as well as providing an

evidenced-based assessment of the issues at hand, and the practical steps that can be achieved to reach now global aims of CVH control by 2030.

Whilst the Commission does not function as a real-time organisation, it provides motivation to the policy community, and builds support in the external frame to support increased CVH testing.

Civil Society Mobilisation: In the original policy prioritisation framework by Shiffman and Smith, policy success is deemed to be more likely if it includes the support and “pressure” of grassroots organisations.

Grassroots patient organisations in CVH are skewed to HCV care, with the British Liver Trust the most vocal of the generic patient advocacy groups. The Hepatitis C Trust is the most well-known of patient charities, and has a formal role and voice at government level through the All Party Parliamentary Hepatology Group (APPHG), with the same founder (Charles Gore) also involved in the World Hepatitis Alliance.

The advocacy achieved through charity work has no doubt been instrumental in raising the profile of CVH, with likely impact at the government level given its formal links and publications. The Hepatitis C Trust has also raised high profile legal challenges to NHS England with regard to the access availability for DAA treatments to patients with HCV.

These patient charities, and medical multidisciplinary teams in the form of HCV Action have produced studies to identify deficits in CVH testing, through submissions to community actors, such as CCGs and Local Authorities. The impact of these interventions should be to improve the awareness and uptake of testing activity in these institutions. However, the ability of these groups to reach primary care physicians and the lay public is less clear, and the reach of these organisations would seem less than the reach or power of patient advocacy groups in HIV, where public recognition and political support as a result is more established.

Ideas: Internal and External frames

The concept of “ideas” and “framing” in the priority setting framework looks at how the policy issues are understood and portrayed, both inside and outside the (stakeholder) policy community. It considers the degree in which the policy community agree on the policy problem; its definition, causes and solutions, and how the policy issue is portrayed in this internal frame, as well as the public (external) arena [Walt G 2014].

In the NICE guideline development process, and within the stakeholder community, there is recognition of the uncertainties that exist in CVH prevalence rates between different at-risk groups, including migrant communities [Uddin G 2010], and in the optimum strategies that should be employed to facilitate testing; with these issues recognised as formal research recommendations to be met in future reviews [NICE research recommendations 2012]. There is however, broad consensus and support regarding the increased burden of disease that is seen in migrant communities in the UK, and the need to improve our efforts to understand and manage these risks, with supporting evidence delivered to the NICE PDG, and in the internal hepatology communities (with stakeholder support) publications in support of increased testing endeavours [NICE expert papers 2012, Williams R 2014].

The view and frame adopted in primary care towards CVH is less clear, and whilst the RCGP provides education resources to GPs, and remains a stakeholder partner in supportive publications with the (internal) hepatology community, the perspective and frame taken at the ground level with practitioners and the disparate CCGs is largely unknown. And given the limited awareness and uptake of previous national CVH policy drives in primary care [D'Souza 2004, RCGP 2007, APPHG 2008], it is conceivable that CVH is viewed in a different (less relevant) perspective in community healthcare setting.

The External Frame considers how CVH is viewed in the wider public. Historic and current awareness of CVH is poor, with global surveys by the World Hepatitis Alliance (WHA) suggesting that only around 7 out of 10 patients were aware of HCV prior to their diagnosis [WHA HCV Toolkit 2016]. Annual global and national initiatives were established over the last decade or so to try and improve CVH awareness, but many individuals with CVH reported feelings and experiences of stigma in day to day life, with only around 1/3rd of HCV positive individuals having informed their families of their HCV status [WHA HCV Toolkit 2016, WHA world hepatitis day]. Stigmatisation therefore remains a concern in the public perception towards CVH, with many of patients expressing concern that family or community members may treat them differently if they knew about their CVH status, with these concerns most evident in migrant community members that I have treated.

On a more positive note, the recent years have seen an increased media reporting of the huge therapeutic advances that have been achieved with HCV, with wide reporting of the “revolutionary” new HCV cures, and their (initial) eye-watering prices, with tag-lines of a “\$1000 a day pill” across multiple news outlets when Sofosbuvir was first marketed. Patient stories, and publicity from patient charities such as the Hepatitis C Trust, and global government led initiatives to provide and fund CVH treatments on a national scale for the first time are all likely to have increased the positive messages of the treatment success that can be delivered for CVH [Channel 4 blog 16th April 2014; New York

Times December 2015]; with many patients having come to see my in clinic after having heard of these stories through friends or the media.

At the political (public) level, the UK government recently announced official plans to investigate the contamination of many individuals with CVH due to blood transfusions in the 1970s and 1980s, highlighting the iatrogenic route of acquisition in these individuals [Guardian 2017]. However, at the specific level of CVH case-finding in migrant communities, the negative viewpoints portrayed by UKIP and more right-wing British groups may prove more evocative [Guardian October 2014, British Democrats], and have led to a greater degree of stigma associated with testing uptake and testing initiatives at the community level.

Context:

Shiffman and Smith use the notion of “policy windows” to explore moments when conditions align favourably for an issue, as well as “governance structure” that provides a contextual platform for effective action.

Looking at the timeline of events leading up to the development of NICE testing policy (Figure 21), the abandonment of the National Liver Disease Strategy is a key loss in both the profile and oversight of CVH testing.

The National Liver Strategy was modelled on existing collaborative reports, and had received executive political support, with the appointment of Professor Marin Lombard to the post of National Clinical Director for Liver Diseases in January 2010. Political support continued for this post in David Cameron’s

Timeline of HBV & HCV related publications and events 2001-13

2001 Antenatal Screening HBV	2004 HCV Action Plan launched	2006 APPHG publishes audit showing poor uptake of the HCV action plan by PCTs	2008 NICE approves Telbivudine + Entecavir for HBV treatment	2010 <u>Jan</u> : Professor Martin Lombard appointed as 1st National Clinical Director for Liver services	2011 NICE PDG meet to prepare HBV & HCV testing guidelines	2013 NICE publish new HBV guidance (HCV guidance in development)
2002 CMO publishes "Getting Ahead of the Curve", highlighting public health importance of HBV & HCV	2004 NICE approves Peg IFN/Riba for Moderate-Severe HCV pts	2006 NICE approves HCV treatment for ALL pts	2009 NICE approves use of Tenofovir for HBV	2010 <u>May</u> : Coalition Government lead by David Cameron comes into office	2012 <u>March</u> : Health and Social Care Act introduced with widespread reforms to the NHS	2013 Hep C Trust publishes report showing poor co-ordination and planning by the new commissioning services
2002 CMO publishes "Getting Ahead of the Curve", highlighting public health importance of HBV & HCV	2004 Doh launches FaCE-It awareness-raising campaign	2006 NICE approves Adefovir + Peg IFN for HBV	2009 BSG/BASL publish: "A Time to Act", identifying the rising burden of liver disease in UK	2010 <u>Sir Mike Richards</u> report to the Secretary of State highlighting poor provision of HCV treatment in the UK	2012 NICE approves DAA's for HCV treatment	2013 <u>Nov</u> : formal announcement that the promised Liver Disease Strategy has been abandoned
	2004 Hepatitis B: "Out of the Shadows" released calling on better diagnosis + treatment for HBV, as well as universal vaccination	2007 RCGP publishes HCV guidance	2009 Hep C Trust audit identifies poor oversight of the HCV action plan by SHAs	2010 Widespread NHS reforms outlined	2012 <u>Dec</u> : NICE publishes Hepatitis B & C testing guidance	2013 First phase III IFN-free trials for HCV held in the UK

CMO = Chief Medical Officer, DoH = Department of Health, Peg IFN/Riba = pegylated interferon and ribavirin, APPHG = All-Party Parliamentary Hepatology Group, PCT = Primary Care Trust, RCGP = Royal College of General Practitioners, BSG/BASL = British Society of Gastroenterology, British Society for the Study of the Liver, SHA = Strategic Health Authority, PDG = Programme Development Group, DAA = Direct Acting Antiviral

Figure 20: Timeline of HBV and HCV related events and publications leading up to 2013

coalition government, with the remit, budget and timetable of this strategy presented to the House of Commons by the Secretary of State for Health, Simon Burns in July 2011:

“Professor Martin Lombard...remit was to provide clinical leadership to the development of a national strategy for liver disease that matches measures designed to achieve quality improvement (and improvements in outcomes for patients) with the identification of where the national health service might release resources to support them. The National Liver Strategy will be an integrated programme, recommending actions to improve the prevention, identification, treatment, care and support of people with liver disease within evidence-based and dignity assured standards of care. Professor Lombard’s budget for this task (net of core staffing costs) has been £560,000 in 2010-11, and £224,440 in 2011-12. As previously announced” [Parliamentary questions July 2011], website <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110719/text/110719w0006.htm>, accessed 11th March 2013].

However, the development of the radical Health and Social Care Act eventually led to the abandonment of this strategy, with fundamental changes in the provision and commissioning of health services [Jane Ellis, Parliamentary Under Secretary of State for Public Health, Nov 2013].

NICE testing guidance was developed in the most part before the introduction of the Health and Social Care Act, and the recommendations generated would have been directed towards the existing PCTs, and whilst these recommendations were not altered following the Act’s introduction, these recommendations are unlikely to have been aimed at the coordinated CCGs and Local Authority groups who were subsequently tasked with CVH testing practice.

Both the loss of the National Liver Disease Strategy and the development of the Health and Social Care Act are policy window points, at which the loss of intervention, and the failure to integrate and coordinate testing responsibility would have impacted CVH testing provision.

More recently, the raised profile of new-HCV medications created an opportune moment to introduce targeted awareness-raising sessions in migrant communities, particularly given the positive messages of the existence of “effective cures” for these viruses. However, there has been an absence of organised awareness-raising measures since the DoH programme to approach members of the South Asian community in 2009 [DoH 2009]. To some degree this may relate to the rise of anti-migrant sentiment, and popular right-wing politicians such as Nigel Farage who received significant media coverage and electoral votes in the 2015 general election [Telegraph October 2014].

The development of such effective (and costly) DAA based therapies in HCV has also contributed to the development of 22 Operational Delivery Networks (ODNs), delivering centralised care to geographic regions under the management of NHS England, who have taken on the commissioning responsibilities for these treatments. This has seen a huge increase in the coordination, focus and treatment scale that has been delivered nationally over a very short space of time, with estimates of mortality declines in relation to HCV of close to 10%, as well as reduced transplantation requirements due to HCV even in this short period [NHS England July 17]. A more pertinent aspect to consider here is the shift in focus that these ODNs will take in the future period to try and improve case-finding activity. At present, these groups are focused and tasked with delivering and coordinating treatment, with aims of identifying and treating the sickest patients first, with the added benefit of CQUIN (Commissioning for Quality and Innovation) (financial) resources made available to these ODN groups [NHS England BL1 2016]. These ODN groups will likely move towards HCV case-finding initiatives as time progresses, and similar systems may well be employed in delivering care for HBV, with improvements that one would hope to see in case-finding activity and CVH care overall as a result.

Overall then, the contextual factors leading up to NICE policy development identify the loss of the National Liver Disease Strategy and the introduction of the Health and Social Care Act as key policy windows for (missed) action, with a loss of oversight in testing provision, and concerns of coordination and testing responsibilities that likely continue today, but with hope through the newly developed ODN models to improve case-finding and treatment activity in the future.

Issue Characteristics:

Issue Characteristics within the Policy Prioritisation framework considers the features of the problem, looking at what levels of knowledge exist about the problem; how the policy subject is measured and quantified with regard to its severity and effect, as well as the effectiveness (including cost-effectiveness) and nature of the interventions available to act [Walt G 2014, Shiffman J 2007] (figure 14).

Measure of policy issue

The first consideration in this are the “indicators” of the policy subject, with “problems that are easily measured more likely to gain political support” [Shiffman J 2007]. In CVH testing, there is an inherent gap in the knowledge of physical testing activity, as well as the actual number of individuals who are positive for CVH. Testing activity is split between primary and secondary care, as well as community providers (drug and alcohol services) and prisons, with no central oversight. Central data is also not collected on testing activity, nor on the proportion of those tested who are identified as positive.

CVH is measured and understood with regard to severity in terms of cases collected through multiple providers and surrogate markers, including the complications recorded through the development of HCC, cirrhosis, transplantation assessment (as well as liver transplant recipients), and mortality related to CVH complications.

Rates of CVH are measured through several different streams, with data collection and focus more robust for HCV over HBV in view of the recent availability of highly-effective cures, and the subsequent development of ODNs tasked with monitoring and delivering treatment, with central data fed back to NHS England.

For HCV, PHE reports on prevalence and effect through multiple sources in healthcare, prisons, community services, as well as private agencies, with 30 data sources used in the 2015 report. Current estimates of prevalence rates in the UK are based on data collected now over 10 years ago [PHE 2017, Harris RJ 2012], with data from the Unlinked Anonymous Monitoring (UAM) survey in participating drug users (PWID), as well as laboratory data, and more recently ODN activity providing an overview of HCV incidence and prevalence across the country. Testing activity and patient monitoring is divided across multiple separate organisations in primary and secondary care, as well as prisons and community services, with no routine platforms of data sharing between these organisations, and with communication routes that may be sub-optimal between these actors, relying for example on faxed referrals to specialist hospital based clinicians to assess complex psychosocial patients looked after in community drug and alcohol services. Recently, the National Strategic Group on Viral Hepatitis (NSGVH) was set up England to try better coordinate and record the activity between these different agencies, building on the coordinate oversight bodies already in place in the other devolved UK nations [PHE 2017, PHE Harris H 2017].

Severity of issue:

The severity of HCV can be measured by looking at the Hospital Episode Statistics (HES) in England, developing a picture of those individuals admitted with end stage liver disease, and the complications of HCC, as well as mortality cases related to HCV. However, this relies on accurate data input on patients, as well as accurate coding of data, with inaccuracies as well as missed patient data that may result. Nevertheless, the use of data identifying the complications of end stage liver disease, including HCC and transplantation have had an impact in achieving central recognition, including the call by David Cameron's government [Hep C trust website March 2013].

For HBV, measures of those infected, as well as the severity of this impact is less well defined, with HCV having taken prominence in view of the recent burden of disease and liver disease complications

from untreated HCV, the runaway success of recent treatment developments, as well as the voice of vocal advocacy groups such as the Hepatitis C Trust.

PHE report annually on acute HBV incidence rates detected through mandatory laboratory reporting and sentinel surveillance data, but there are no central reports on the number of chronic HBV cases identified each year, or those who are in, or previously been seen in primary, secondary, or community based services [PHE Acute Hepatitis Sept 2017]. As with HCV, there remains a lack of coordinated testing activity between services, including maternity services, with no central oversight to testing or treatment activity.

A measure of HBV cases is obtained through sentinel surveillance data, taking a snapshot of testing activity, as well as a snapshot of antenatal testing that occurs nationally, with the last official data publication from 2015 [PHE Health Protection Report 2016]. Data monitoring on chronic HBV is otherwise less robust, with mandatory laboratory reporting that was introduced only in 2010, and with wide variations in the quality of key data collection for HBV even across London hospital laboratories [Foundation for Liver Research 2004, PHE Hepatitis B 2012],

Severity data for HBV can be drawn from liver transplant data for the UK centres, as well as HES data, but with the last official PHE publications available on morbidity and mortality complications for HBV in 2012, with HBV constituting 2% of transplant activity in 2015/16 (compared to 6% activity for HCV), and with an increased number of hospital admissions and liver disease complications (including HCC) recorded in 2012 secondary to HBV [PHE Hepatitis B 2012, NHSBT 2016]

Effectiveness of policy intervention:

The effectiveness of CVH testing considers the background prevalence of CVH, the efficacy of treatments available for those who are identified as positive, as well as the efficacy (uptake) of testing activity, with the cost-effectiveness of these interventions a key consideration in this analysis.

Focusing on policy in relation to testing in migrant communities, the NICE testing guideline development process utilised a commissioned cost-effectiveness analysis from the London School of Hygiene and Tropical Medicine on CVH testing in UK migrant populations [Miners A 2012]. In this analysis, the authors considered the incremental cost-effectiveness ratio (ICER) of testing interventions, modelling assessments with assumed variables based on disease prevalence, testing uptake, the numbers subsequently requiring treatment (for HBV), and the effectiveness of treatments; modelling a hypothesised testing event compared to the standard of care, where no structured testing occurs, and taking into account the inherent difficulties that exist in the current CVH data set [Miners A 2012]. ICERs were developed for HBV and HCV, and compared to (NICE) established quality-adjusted

life year (QALY) thresholds (of £20-£30,000) designed to give an overall measure of health outcomes weighted to the life expectancy of the patient, and an estimate of their health related quality of life (HRQoL) outcomes [NICE guidelines manual 2012].

During their analysis, the authors modelled a HCV prevalence rate of 2% in the population tested, with testing activity expected to increase to 17% with new intervention, and costs of £50-75 per individual tested, predicting cost-effective ICER QALY thresholds of £20,000 through these predictions. For HBV, assuming the same prevalence of 2%, ICER values of £21,000 were calculated, which were thought acceptable in view of the variables and uncertainties used in modelling calculations [Miners A 2012].

The cost-effectiveness findings of the NICE development group are further supported by other global studies, including a systematic review of cost-effectiveness in CVH testing, funded by the ECDC (European Centre for Disease Prevention and Control) in 2015 [Geue C 2015]. In this analysis, modelling was seen to vary based on the background prevalence of disease, the testing strategy adopted, and the treatments available, with newer studies demonstrating improved ICERs in testing and treating for CVH [Geue C 2015]. Modelling studies in this analysis considered screening, as well as case-finding in at-risk groups, including HBV testing in migrant populations, which was identified as a risk-group to continue monitoring [Geue C 2015]. For HCV, case-finding, and screening is also discussed in this systematic review, with now outdated protease based regimens providing more favourable ICERs than conventional therapy, with ICER values of £23,000 per QALY gained achieved in these Protease-based intervention arms of HCV therapy [Geue C 2015]. Further support for the cost-effectiveness of HCV testing (screening) is available from the US, with a well-publicised drive to increase birth cohort testing.

The advent of DAA therapies in HCV has also led to considerable advances, with a recent study from South Korea identifying ICERs from \$5,714 to \$8,889 per QALY for HCV, utilising DAA based therapies, with a modelled (HCV) prevalence estimate of 0.6 to 1.53% in the background population, but with a well-established HBV screening programme that is already in place nationally [Young Kim D 2017].

The effectiveness and uptake of CVH testing activity is difficult to qualify, and is likely to vary based on the intervention, or lack of intervention adopted. In studies in the US as part of the HCV birth-cohort testing programme, intervention with testing prompts via letter, or electronic health record prompted physician interaction identified more individuals as compared to standard (no intervention/prompting) testing, with testing uptake of 27% vs 1.4% in mailed invite studies, and 31% vs. 3.6% in electronic health record prompted physician interactions [Brady JE 2017]. In the NICE cost-effectiveness analysis, an uptake of 17.5% was taken in modelling estimates over a 6-month period following the introduction of a testing intervention. This estimate was taken based on an earlier pilot

opt-out study based in East London primary care, where South Asian registered patients were given mailed, and then phone based invites to attend for testing, with an uptake of around 20% of the sampled population, and with an expectation that uptake rates in a stable population may then return to a low level after the initial intervention period [Miners A 2012, Lewis H 2011].

However, the final NICE CVH testing document does not identify a standardised way to “intervene” to identify and offer testing, with uptake rates that are then difficult to estimate in a standardised way across primary care [NICE 2012]. Without a standardised testing activity, the actors (individual practitioners or departments) involved in testing activity is also not defined in policy, with difficulties that exist therefore in identifying the potential complexities that testing may pose on a regional or national scale [Walt G 2014].

The efficacy of treatment for CVH, and the rationale to identify infection is however well defined. In HCV, DAA therapies can provide cure in 95-100% of cases [EASL HCV 2016], and with nucleoside/nucleotide analogues that can provide complete viral suppression in HBV in 97-99% of cases, and prevent or reduce the risks of onward progression to HCC, cirrhosis, and end-stage liver complications [EASL HBV 2017].

Outcome:

The concept of an “Outcome” category was added by Walt and Gilson to the original Shiffman and Smith priority setting framework; with the aim of understanding how seriously the policy objective is taken and its likelihood therefore of being put into practice [Walt G 2014].

This aspect of the framework considers the authority and decisiveness of the policy decision, the resources allocated to deliver it, as well as the hierarchy and relations of the actors involved in the policy process. Given the complexities and sensitivities of many topics, policy objectives and decisions may not be clear, with opposing views held among actors, or there may be a lack of data to guide single actions that will address the policy issue. The hierarchy of those involved in championing policy is also important, as well as considering the resources that is allocated; across technical, financial and human resources perspectives [Walt G 2014].

NICE CVH testing policy is a Public Health document, and therefore not designed to be adopted in the same mandatory format across the NHS as Technology Appraisals, but nevertheless is designed to provide clear and authoritative practical strategic recommendations that can be readily implemented by practitioners [NICE Process and Methods 2012].

NICE CVH testing policy does accordingly provide clear recommendations to community services (principally in primary care) to guide testing activity:

“GPs and practice nurses should offer testing for hepatitis B and C to adults and children at increased risk of infection, particularly migrants from medium- or high-prevalence countries and people who inject or have injected drugs (see Whose health will benefit?).”

“GPs and practice nurses should offer testing for hepatitis B and C to people who are newly registered with the practice and belong to a group at increased risk of infection (see Whose health will benefit?).”

However, as identified earlier, there is a lack of direction into how testing should, or could be achieved, with the suggested responsibility placed on practitioners to pursue an unknown, self-directed route to testing activity. Whilst new-patient testing is suggested as a strategy to CVH testing, there is little structured advice about how this can be delivered, with many practices having abandoned clinician or nurse based assessments at new-registration visits; opting rather for paper based forms and reception interaction [personal discussions with primary care physicians]. There is also the need to cross-reference with the “whose health will benefit” section at each point, even with migrant groups, where the geographic scale used to reference migrants approaches a continent level, rather than a more concise or nuanced definition. Although NICE guidance has a specific “implementation” tool section, this process fails to provide any examples or recommendations of how testing delivery can be achieved in primary care or the local authority level, where the majority of testing work, and coordination of health to secondary services should take place [NICE Practice-based implementation 2012]. Community groups who interact with migrant populations are also included in NICE recommendations as possible actors to facilitate testing, but again with little structure or practical guidance as to how this can be delivered, or integrated to primary care.

As such, the lack of clarity in practical application limits the decisive authority that the core message of NICE testing policy may achieve. And in addition, the responsibility to audit and drive testing activity is left to the newly formed Local Health and Wellbeing Boards; made up of separate PHE, Local Authority and CCG organisations [NICE 2012], with a lack of central or regulated oversight to see that testing and monitoring is taking place.

Political Support:

Political support for CVH has been demonstrated at the highest level in official statements issued by David Cameron, and whilst his successor Theresa May has vocalised support for a greater focus on HCV as an MP, in her role as PM her support for CVH has involved a formal enquiry into the

contamination of blood supplies [Maidenhead MP 2006, British Liver Trust November 2017]. Rather political support for CVH is most evident in the increasing role and funding provision provided by NHS England under the Department of Health to treat HCV with new DAA based therapies, with the real goals and support to help meet the objectives of the Lancet Commission and others to achieve an elimination target of HCV by 2030. And whilst current focus and high-level support is directed towards CVH treatment (and in particular HCV), there is a growing recognition of the need to move towards improved CVH testing, with an impact that should be seen in the core aims of NICE CVH testing policy [NHS England Blog July 2017, Williams R 2014, British Liver Trust November 2017].

Support at the provider level is also evident with the multiple separate CCGs issuing publications to advocate awareness raising for CVH linked to World Hepatitis Day, and with e-learning modules in CVH promoted by the RCGP, albeit with the recognised difficulties that GPs now have with trying to squeeze additional practice learning points into ever demanding work pressures [RCGP elearning 2017]. Support for CVH testing at the community level is also likely to be influenced by a historic background of low levels of awareness and understanding of CVH [RCGP 2007], and with the ongoing lack of a systematic vision or oversight that is in place to conduct and monitor testing in primary care.

Resources:

No specific financial resources are mentioned in NICE CVH testing policy, with no additional or dedicated funding allocated to testing. An estimate of potential costs is presented in supporting NICE guideline documents, with cost estimates presented over a 5 year period, but is based on many uncertainties that exist in underlying prevalence rates, and older treatment regimens for HCV [NICE costing template 2012].

These costs are presented as a cost to the NHS, with CCGs tasked with commissioning this activity, without clear reciprocal demonstration of the savings estimates that may be achieved at the CCG level through this activity. Although potential costing templates are offered to help commissioning groups understand the financial implications of testing (based on these groups measuring and calculating their own prevalence rates), these are presented at the (now disbanded) PCT level. Financial considerations in the supporting policy documents were also unable to fully predict the role that NHS England would take in commissioning all treatments for CVH, and therefore to remove this budgetary need from CCG financial considerations [NHS costing template 2012].

Additionally, there is no recommendation to include any financial resource incentive schemes towards CVH testing, such as the Quality and Outcomes Framework (QOF) in primary care, despite these incentives being advocated by patient charity groups, and by clinicians in the field with the hope of

increasing the awareness and practice of CVH testing [Commons Select Committee 2011, Williams R 2014].

Technical resource limitations are also apparent in CVH testing policy, with the inability to foresee the arrival and complexities of the incoming CCGs, and the newly formed Health and Social Care bill, as well as the inherent uncertainties that exist in the underlying prevalence and uptake of CVH testing in estimating community models. The implementation tools offered in conjunction with the NICE guideline document are also limited by these data uncertainties, and in providing practical direction. There is also no mention of any technology based approaches that can be used to facilitate testing, such as electronic coding data, or the linkage of data across separate provider services which could be used to develop and facilitate better testing and treatment programmes, as well as help support separate organisations explore potential data merging across Information Governance obstacles.

The rapid pace of change in recent treatment developments was also not predicted in guideline development, with many of the original supporting documents, and effectiveness estimates that would be expected to perform better in the current era of CVH treatment options.

Human and technical resource limitations are also apparent in CVH testing policy, with a failure to link testing activity to a dedicated oversight body, or group of individuals, with a reliance rather on self-directed testing and monitoring responsibilities run by Local Health and Wellbeing Boards; made up of separate PHE, Local Authority and CCG organisations [NICE 2012]. There is no national monitor of CVH testing activity, or rates of infection nationally, and only recently in 2017 did the first indicator of liver disease appear in the NHS Outcomes Framework, with liver disease mortality (in the under 75s) now monitored nationally as one of the NHS outcome goals [NHS digital Feb 2017, Williams R 2014].

Taking these resource considerations together; the lack of dedicated funding mechanisms and oversight responsibility /accountability for testing activity leaves one to presume that the human resource priority that is actioned towards testing activity at the practice / community level, as well as higher CCG or Local Authority level is therefore likely to be low.

Key Findings:

NICE hepatitis B and C testing policy was developed to raise awareness of HBV and HCV, and to improve CVH testing; being developed with high level political support in the face of a growing mortality seen in relation to liver disease, and HCV in particular. NICE CVH testing recommendations are directed towards community services, with primary care the principal group with access to these

at-risk individuals, and migrant groups in particular. Testing recommendations are far-reaching in comparison to other policies across Europe at the same period, with a specific focus to provide testing in migrant communities. However, previous national CVH testing policy endeavours received low levels of awareness and uptake in clinical practice, with particular deficit in primary care, and with concerns then that current testing policy may meet with a low priority that impacts its' adoption and implementation.

The Policy Prioritisation Framework developed by Shiffman and Smith, and furthered by Walt and Gilson provides a structure to understand the factors that influence policy reaching the political agenda, and receiving the attention and resources for its implementation. In the context of this thesis, the framework looks to establish how CVH testing policy in migrant communities can achieve this political priority; considering the concepts of Actor Power, Ideas, Political Context, Issue Characteristics and Outcome in assessing how migrant testing can be prioritised.

- **Actors:** The actors involved in policy development are supportive of its' objectives and implementation, but without clear leadership that is identified, and with policy that was designed largely in a top-down approach, with little evidence of community involvement and incentive in testing objectives.
- **Ideas:** there are uncertainties that exist in our understanding of CVH risks, and how to best achieve testing. The internal community remains committed to endeavours to improve current activity, but the view and commitment at the primary care (ground) level is unclear. At the external frame, the public are likely more aware of CVH through recent (positive) initiatives and developments, but concerns of stigmatisation remain, particularly in migrant communities.
- **Context:** CVH testing policy was developed with high-level political support, with national oversight that was developed at the same time through the National Liver Strategy. The introduction of the Health and Social Care Act does not appear to have been predicted, or factored into CVH policy, with the subsequent loss of the National Liver Strategy. The recent introduction of the ODNs, and central role played by NHS England may provide greater coordination and oversight of CVH case-finding and treatment going forward.
- **Issue Characteristics:** there is ongoing uncertainty in the measures used to currently monitor CVH testing, with no established oversight (coordination) of testing activity. The severity of CVH can be assessed through surrogate markers in hospital statistics, but there remains gaps in our understanding of the effective (practical) routes to achieve testing uptake in heterogeneous at-risk groups, including migrant communities. Previous (positive) cost-

effectiveness assessments of CVH testing are likely to be improved in consideration of the vast improvement in treatment options and treatment uptake.

- Outcome: Whilst there are clear recommendations to primary care and community groups to action testing in migrant groups and other at-risk groups, there is little in the way of practical direction as to how this can be achieved, reducing the authoritative decisiveness of policy. Dedicated resources to facilitate testing are difficult to find, with a lack of financial and human resources that are additional or identified from policy. The development of the newly formed ODNs, and recent drives in the wake of DAA successes may however act as a resource to facilitate policy objectives.

Chapter 4

Focus Group studies in the UK Nepali community:

The awareness, knowledge and perception of liver disease among members of the local community

Chapter 4: Focus Group studies in the UK Nepali community: *The awareness, knowledge and perception of liver disease among members of the local community*

Focus group discussions in the Nepali community:

Abstract:

Whilst policy can achieve improved CVH testing activity in a top-down approach, it is dependent not only on the ground-level actors who provide testing (principally in primary care), but is also dependent on the awareness and perception of disease in the migrant communities served, with particular difficulties that are faced in developing strategies to engage with new migrant communities such as the UK Nepali community, where disease risks and health engagement patterns are unknown.

Developing an understanding of the factors that may influence underlying CVH health risks in the community, and the awareness and perception towards liver disease is important in developing practical CVH testing and management strategies, as well as developing and maintaining long term health engagement patterns in this new migrant community.

Context:

Patterns of healthcare engagement are known to differ in migrant communities, with concerns that some may present late in their disease process, or to not interact with conventional healthcare services; adding to concerns regarding the health vulnerability of these individuals.

The underlying factors that may affect healthcare interaction can be complex, and include previous healthcare experiences, national and transnational ties, as well as factors influencing health access in the host country. Understanding the awareness and perception of health and health engagement is important in developing strategies to reach out to these communities, in understanding underlying health risks, and in developing effective testing and management interventions.

The UK Nepali population is a new migrant community, with little known about health awareness and perception, and how the community would engage with CVH testing endeavours. Understanding these factors, and any potential facilitators or barriers towards testing delivery and uptake is important in endeavours to improve CVH testing, and future health engagement.

Literature Review:

Awareness, understanding and perception of disease (CVH) in migrant communities:

Factors that influence health-testing uptake are multifactorial, including those aspects that lie at the practitioner level, the system structure, as well as the patient. Language barriers are well known to be a factor in patient-practitioner interactions, but developing successful testing engagement

endeavours require a more detailed understanding of the awareness, beliefs and attitudes relating towards disease states, and disease management [Cochrane A 2016].

Migrant communities may have different health perceptions, as well as differences in health-seeking behaviour that may be linked to cultural experience or transnational ties [Norredam M 2010, Kessing L 2013]. Culture and traditional beliefs may also impact on the perception and treatment paradigms that individuals may follow, with a role for Spirits and other external agents that individuals may see in controlling their disease process, and in how this may influence health-seeking behaviours [Uehara ES 2001]. Indeed, the baseline complexities (fragilities) of migrant groups native social and cultural history and circumstances, including tragedy and displacement is likely to influence how wellness and disease is perceived, and is likely to influence health-seeking behaviour, as suggested in studies in the US Cambodian population [Uehara ES 2001]. Previous systematic reviews have shown that migrant groups may be less likely to engage with cancer screening services, and that there are often complex multi-faceted reasons for this lack of health-engagement that seems independent of, and more than a mere lack of knowledge relating to disease implications [Kessing L 2013].

In CVH testing, stigma is described amongst patients with diagnosed HBV and HCV, and is mentioned as a possible barrier to testing in several qualitative studies in migrant communities [Drazic NY 2013, Rafique I 2014, Sriphanlop P 2014]. Studies conducted within South Asian countries suggest that the level of stigmatisation and isolation felt by viral hepatitis patients here in the native country, may be greater than that elicited by South-Asian migrants in Western countries. Direct comparisons between these groups are not possible, and differences may be accounted by multiple factors; including socio-economic status, socio-cultural, religious and environmental factors; but the strength of assertion made by patients' resident in South Asian countries raises the potential for greater perceived stigma in new members from these communities [Drazic NY 2013, Rafique I 2014].

However, not all migrants see stigma in their condition within their community [Cochrane A 2016], and there are likely to be differences in how HBV and HCV are seen. The impact of stigma alone as a barrier to testing is unclear, and studies in the UK among migrant-community healthcare leaders have suggested low levels of awareness in testing programmes as perhaps a more important factor in uptake, and despite stigmatisation expressed by migrants, there seems to be a high level of acceptability towards the delivery of better coordinated testing services in community settings. [Seedat F 2014].

Knowledge regarding HBV and HCV is universally low in reported studies, and liver disease is often understood and referenced as jaundice in qualitative studies [Cochrane A 2016]. Although stigma is mentioned by migrant groups in focus group studies on viral hepatitis, most express the consensus

view to learn more about viral hepatitis, and to engage in community intervention programmes that will offer individuals long-term benefit [Blanas A 2015]. Focus group studies in migrant populations commonly cite cultural and religious factors as drivers to support testing, with Islam often used to support testing and treatment as part of one's overall health responsibilities [Blanas A 2015, Van der Veen YJ 2009]. These studies also identify differences that exist between sexes and age groups towards how disease is viewed, and in potential barriers and facilitators to testing. Older individuals may express less stigmatising factors, but express externalising factors in controlling health-states that may itself impact testing and engagement [Van der Veen IJ 2009]. Adding cultural and religious (Islam) framed support for testing has been assessed in the Dutch Turkish population, but without any significant difference in testing uptake compared to simple mailed invites alone [Van der Veen YJ 2010]. However, the authors reported a high level of satisfaction with these methods, and such testing approaches with religious and/or cultural framing may be beneficial in groups who express strong stigmatising perceptions, or with groups that are particularly difficult to engage with [Rafique I 2014].

Cultural perceptions towards health, illness and therapy vary between communities. In the study by Burke et al. into HBV perceptions in the Cambodian American (US) population; traditional paradigms of health were seen to mix with modern approaches in the US, demonstrating a medical pluralism that exists between traditional models of health and modern day medical practices. Suffering is often viewed as an integral and inevitable part of life and happiness, and some participants in the study reported the use of dermabrasive techniques with pinching or coining (rubbing the skin with a hard object, such as coin in a linear fashion) in an attempt to manage illness [Burke N 2011, Tan AK 2011]. Participants in the group also reported seeking traditional Western healthcare consults only after having tried these traditional methods, with the concerns therefore of delayed healthcare presentations despite clinical concerns [Burke N 2011]. Levels of understanding towards CVH was poor in the focus groups conducted, with many aware of specific medical terms through formal healthcare interaction, such as hepatitis A, B and C, but associating this to a step-wise progression that occurs due to a lack of self-care, progressing from HAV to HCV, and beyond to severe complications. The majority of participants (n=97) had been in the US for over 10 years, and whilst the views above were not expressed by all, there is evidence of significant variation in healthcare beliefs and practices that would adversely affect healthcare interactions, and CVH care specifically, with a pluralism of beliefs that seem detrimental [Burke N 2011].

Overall, these studies demonstrate that there is heterogeneity between communities in how health and disease awareness and perception, with complex national and transnational ties that are likely to underpin this, as well as health access and integration factors in the host nation. Improving awareness

of disease and the benefits of treatment is widely expressed as positive facilitators in testing, and health uptake. Awareness of CVH is likely to be low in most migrant communities, and is commonly understood as “jaundice” or “liver disease” in qualitative studies [Burke N 2011]. , and whilst stigmatisation is widely mentioned, it does not feature as a non-modifiable barrier to testing, with large educational campaigns able to de-stigmatise viral hepatitis, moving stereotypes away from the “bad-individual” to the management of a chronic disease state that is geographically prevalent [Yoo GJ 2011].

Exploring the perceptions towards health and treatment in migrant communities can help identify fixed beliefs that may be held, and pluralisms that may adversely affect healthcare engagement and treatment abilities, with intrinsic (self) and extrinsic (e.g. spiritual) factors that may be evident.

Research Objectives:

In looking to develop and improve the provision of CVH testing and onward care in the Nepali community, we sought to first understand the awareness and perception of disease to achieve the following research objectives:

- To explore the awareness of liver disease in the Nepali community
- To explore the knowledge and understanding of liver disease related to aetiology, pathogenesis and treatments.
- To explore the perceptions of the community towards liver disease, considering its priority, severity, and perceived risk factors.
- To explore perceptions towards treatment paradigms and healthcare interactions in the UK
- To understand perceptions of stigma towards liver disease, and potential barriers and facilitators towards CVH testing, and factors that may influence the development of CVH testing initiatives in the local Nepali population.
- To inform and shape the development and delivery of a (future) community CVH testing initiative in the UK Nepali population

An overarching objective with our Focus Group work was to help develop a culturally-sensitive approach to the development of a community CVH testing study, with focus group studies conducted as the first part of this approach, and framed as first part of our study aims in formal ethics applications for our research work.

Focus Groups – background and rationale: Focus groups were chosen to explore our research objectives given their pedigree in qualitative studies, and given their utilisation in prior studies in migrant health.

Focus group were first widely utilised in political and market research, before being adopted more widely into health and social sciences [Braun and Clarke 2013]. Focus groups allow the researcher to explore the understanding and perception of multiple participants, benefiting from the shared social interaction and discourse facilitated through group discussions [Braun and Clarke 2013]. These discussions can be help identify personal opinions that exist, as well as those that are shaped or arise through group discourse, replicating opinions that exist and form through social group interactions [Krueger 1994].

Focus groups offer particular benefit in exploring the perceptions of under-represented and marginalised groups, where the group can help facilitate expression, and to give voice to individuals who may not otherwise be express themselves in other settings [Braun and Clarke 2013]. In a similar way, focus groups can also help explore sensitive topics, where the non-formal and relaxed group environment can help facilitate discussion and opinion [Braun and Clarke 2013]. Focus groups have therefore been employed successfully among diverse patient groups to explore perceptions in sensitive areas such as HIV, injecting drug use, as well as viral hepatitis [Frew PM 2016; Lindkvist P 2015; Sweeney L 2015].

In migrant health, focus groups have been well utilised in exploring knowledge and perceptions towards health and disease states, as well as health seeking behaviour, allowing the researcher to explore the opinions and shared cultural beliefs of individuals through these sessions [Burke NJ 2011, Cochrane A 2016, Sweeney L 2015; Vatcharavongvan P 2014]

As with all qualitative methods, Focus Groups do have their disadvantages, which include a loss of detailed personal experience and narratives, as well as the effects of group heterogeneity in discussions and the relative loudness of particular participants in expressing opinions that may mask those of others [Krueger 1994, Braun and Clarke 2013]. However, overall focus groups are a well proven method of exploring new and sensitive information among migrant communities, and provides a level of meaning making [Braun and Clarke 2013] that can be employed to explore factors relating toward knowledge, perception and influencing factors on healthcare access and engagement in new communities such as the UK Nepali population.

Awareness, knowledge and perception: The concepts of “awareness, knowledge (understanding) and perception” are related, and not mutually exclusive. Rather they sit on a spectrum, with relationships that exists between these concepts and that influence one another.

These terms are often used interchangeably, and dictionary definitions further the difficulties in distinguishing clear distinctions between them. But for the purposes of this thesis, awareness is used to reference a “general awareness” of liver disease, and utilises the concept of a knowledge continuum where knowledge is referenced as “detailed and specific knowledge”, which sits at the opposite end this continuum. Whilst these terms are not distinct, I use the concept of awareness to establish the general and reflex awareness of the community towards liver disease [Trevethan R 2017]. This awareness is dependent on personal experience, and is reflective of an almost visceral response to the condition, that relates to the severity in which the condition is seen, and that of course feeds into the knowledge and perceptual domains extracted throughout focus group discussions.

Knowledge and understanding is explored as a more detailed concept [Trevethan R 2017], considering the aetiology, risks, and treatment experiences in the community, based on lived experience and learned knowledge. This knowledge is therefore taken to be a more detailed account and analysis of the experiences gathered during focus group discussions, that identify the knowledge and certainty in the community towards liver disease.

Perception of a disease is related to one’s awareness and knowledge, and in the absence of any awareness of liver disease, one’s perception will be very different to a person with first-hand experience [Dretske F, 2006]. Perception is therefore very much dependent on one’s lived, and learned experiences. Perception is not taken as separate to awareness or knowledge, but is used in this thesis to explore the community’s views towards liver disease, its causes, and certainties of association, therapy, as well as stigma. Stigma features within the realm of perception, including public stigma, with the perception that is held within wider society, and self-stigma with the internalisation of perceived prejudices that they may encounter, and the onward implications that these may have [Latalova K 2014].

Reflexivity:

In looking to engage with members of the UK Nepali community for the first time, I became aware of the importance of understanding the awareness and perception of viral hepatitis and liver disease in this migrant community. Working as a clinician, one often approaches disease states and management decisions in a dogmatic fashion, following a well-established medical model.

Understanding the awareness and perception of health and disease in the patient is not often considered, and the access and effectiveness of health care approaches may be negatively impacted as a result. I therefore adopted this qualitative work with great interest, and intuitive qualities, to explore how liver disease was understood and perceived in the Nepali community, and remained mindful of my own limitations in not involving these considerations in my previous clinical work.

Methods:

Focus group sessions were designed along the principles identified by Krueger and Braun and Clarke [Krueger 1994, Braun and Clarke 2013].

We developed a research steering group, involving Nepali community leaders in order to identify potential focus group participants. Nepali community leaders were identified with the help of hospital community liaison leads from Frimley Park Hospital, Nepali nursing staff, local council leads, and the Rushmoor Healthy Living social enterprise charity. Ramji Tiwari was identified from Rushmoor Healthy Living as having had Public Health experience in Nepal, and was involved as one of the core members of the research steering group.

The role of Nepali community leaders was vital, and given the religious heterogeneity and the lack of existing infrastructure in community healthcare links, we developed this group from its infancy, drawing in many Nepali community volunteers and stakeholders as the project evolved. A more detailed description of this process is presented in the CVH testing study chapter.

Focus group participants were identified with the initial members of our Nepali steering group, made principally of nursing staff, hospital liaison links (Kathryn Stuart) and Ramji Tiwari, working with Rushmoor Healthy Living. Formal academic input and qualitative support was provided by Dr Jane Hendy from the University of Surrey (now Professor Jane Hendy at Brunel University).

In keeping with early discussions among our Nepali colleagues, focus group discussions were delivered in Nepalese, with Nepalese speaking (bi-lingual) moderators identified from our steering group (Ramji Tiwari, Mrs Tiwari, and a Nepali nursing student at Frimley Park Hospital and the University of Surrey). English was felt to be poorly understood in the recently arrived community, and moderators were given face to face verbal training in conducting focus group work prior to undertaking sessions.

Focus group sessions were held in the Rushmoor Health Living centre in central Farnborough, in a popular shopping area familiar to most locals and Nepali alike, with sessions held in a neutral community environment. Clinical members of the team were not present during discussions to try and encourage natural discussions in familiar settings. Self-moderated focus groups were chosen given

their potential benefit to de-formalise sensitive discussions, and to encourage certain aspects of discourse in a more culturally appropriate setting [Braun and Clarke 2013].

A formal national ethics process was completed prior to commencing our study, with application through the national NHS Health Research Authority (HRA), and a favourable opinion granted through the South East Coast HRA committee (REC 12/LO/1530) [Appendix 2]. Ethics application for our Focus Group work was submitted as the first part of a study to inform and develop a subsequent CVH testing study in the UK Nepali community [Appendix].

Focus group guides were created (Dr Jane Hendy) to elicit discussions relating to our research objectives. Focus group guides were used universally across all 4 focus group sessions. Moderators primarily used the term “liver disease” in discussions, given our level of uncertainty how specific disease references such as viral hepatitis, or hepatitis B & C would be understood, as well as our desires to explore broader concepts of how liver disease was perceived, and in identifying broad factors that may influence healthcare engagement.

Participants were purposively identified through input from our community leaders and stakeholders, including the hospital liaison team at Frimley Park Hospital. Participants were invited by a standardised letter, as well as personal (word of mouth) invitation from our Nepali volunteers.

It was recognised in early discussions that many of the recently arrived Nepali were likely to be older, and in an attempt to improve representation, our Nepali community group suggested recruitment invites to be targeted to Nepali participants above or below 30 years of age, with these definitions maintained during analysis. Four focus groups were therefore organised,; inviting male and female participants with ages above or below 30 years to participate.

Focus group guides were used universally across all 4 focus group sessions. Moderators primarily used the term “liver disease” in discussions, given our level of uncertainty how specific disease references such as viral hepatitis, or hepatitis B & C would be understood, as well as our desires to explore broader concepts of how liver disease was perceived, and in identifying broad factors that may influence healthcare engagement.

Focus group sessions were audio-recorded, transcribed and then translated with help from Nepali speaking members of our advisory group (Ramji Tiwari). Participants were given written information and consent sheets in Nepalese and English detailing the aims of our study, as well as how information would be recorded and processed. The importance of sharing thoughts in a confidential area, as well as the lack of a “right-or-wrong” answer was stressed to all members before starting each group. Each focus group session was audio-recorded.

Moderators were given autonomy to phrase questions as they felt best according to each group, and to explore additional avenues related to liver disease if they arose during discussion. Feedback was taken at the end of each session to gauge for sensitivity provoked by questioning/comments.

Data Analysis: Thematic Analysis

Several qualitative data analysis methods were considered in the context of focus group data that would require translation and transcription from Nepali to English, and with expert opinion garnered through the qualitative data analysis workshops: “Introduction to Qualitative Data Analysis, Surrey Social Sciences School”, Dec 2015; and “Doing and Communicating Qualitative Research Summer School 2016”, Kingston University.

A thematic analysis (TA) approach was eventually chosen given its proven utilisation in focus group analysis, as well as its relative flexibility in providing an inductive bottom-up approach to explore the ideas and concepts expressed in focus group discussions [Braun and Clarke 2013].

Alternative data analysis strategies including interpretative Phenomenological Analysis (IPA) were also considered prior to adopting a TA approach, with IPA initially reviewed given its experiential (lived experiences) approach to identifying patient meaning and sense-making [Braun and Clarke 2013]. IPA may provide richer data analysis and coding at the individual participant level, focusing on the characteristics and meanings expressed by each participant. However, the role of IPA in focus group analyses of multiple participants is less established [Tomkins L 2010]. The loss of interpretative quality that occurs through the translation process from Nepalese to English is also not well described, and is likely to lead to a loss in the quality of experiential analysis that will arise. The choice of qualitative methodology was made following my attendance at formal qualitative workshops held at the University of Surrey and Kingston University.

Thematic Analysis was therefore used in focus group analyses to explore the ideas and concepts (meanings) expressed in participant groups, utilising a RE (Realist Evaluation) framework to generate associations from these discussions. Initial coding was performed by myself as the primary researcher, with higher organising themes presented and discussed among the research team with the principal study supervisors.

Overarching themes from TA were then analysed to explore how these findings may impact the way that the Nepali community interact with CVH testing.

Results/Analysis

32 Nepali individuals attended the focus group sessions with all individuals born in Nepal. Groups were divided according to sex and age; males and females above or below 30 years of age. The average number of focus group attendees was 8 (range 6-11), with each session lasting 30-60 minutes.

Question guides were used to structure each focus group, with additional avenues of thought explored by the moderator if felt appropriate. Open-ended questions were posed, with broad themes exploring the definition of liver disease, the causes of liver disease and personal experience, as well as how liver disease is viewed in the Nepali community.

Focus group guides were developed by Dr Jane Hendy, with 10 key questions (table 10) designed to explore the awareness and perception of liver disease in the Nepali community, with specific aims to identify potential barriers and facilitators that may exist in the subsequent development of a CVH

Focus Group Guide used by Nepali moderators (key questions):
Can you tell me - what do you think liver disease is?
<i>Prompts: Is it infectious, is it fatal, how do you know you have it, how do you get it, what can you do if you have it?</i>
What sort of people do you think are most likely to get liver disease?
<i>Prompts: young, old, lifestyle factors (drinking, drugs), dirty/clean, and other beliefs, including religious?</i>
Do you know anyone who has ever had liver disease?
Can you tell me about them?
What do you think happens to you if you have liver disease?
<i>Prompts: what type of things might you notice; can you be cured? What does the cure involve? Do you die?</i>
Tell me what you think might cause liver disease in the Nepali community?
<i>Prompt: how might this be different for other groups of people?</i>
What do you think Nepali people think about others who have liver disease?
When I say hepatitis - what does this word mean for you?
How would you go about finding out more about health issues liver disease?
<i>Prompt: where and why?</i>
What sort of information would you like? What is most useful?
<i>Probe: for brochures, booklets, flyers, newspaper articles, videos, television)</i>
<i>Do you prefer information in English or Nepalese?</i>

Table 10: key questions posed to the focus group members (all 4 groups) by the moderator

testing study. Questions were also designed to explore potential risk factors that may exist in the community towards liver disease, and how future education and health engagement may best be delivered to the community. Moderators were briefed to explore the role of traditional cures and disease paradigms in the Nepali community, including the role of extrinsic agents such as Spirits and Witch Doctors. These traditional beliefs were explored during discussions, with particular relevance given their strong emphasis in some of the early focus groups among older male participants.

Analysis results:

Males Under 30:

Two overarching themes were identified in our focus group session in males less than 30 years: Uncertainty, and the need for constant vigilance, and Responsibility and Impact. An overview of these themes and their candidate themes is presented in table 11, with a network map in figure 21

Uncertainty and the need for constant vigilance

An overarching theme that reflects the struggle participants expressed in defining liver disease, its causes, as well as how one could guard against a disease with a myriad of often conflicting causes. The theme “liver disease is (nearly always) jaundice” explores how liver disease is largely experienced as a short-lived episodes of transient illness, with Jaundice often considered as an almost separate disease state affecting the liver, rather than a manifestation of disease. “How do we explain illness” explores the almost universal difficulties participants expressed in knowledge regarding the causes of disease, and the unpredictable nature of disease and disease recurrence. The theme “external causes of disease” looks at the strongly expressed beliefs of external agents such as food and water that can cause disease, as well as spirits that cause disease. “Universal risk and constant vigilance” encompasses the participants concern and uncertainty regarding how to protect against disease given its many potential causes, and external agency. “Traditional vs. medical (scientific) therapy” explores the participants predominant views on the place of faith, and traditional based therapies in early disease management, but also the uncertainty and place of modern medicine in providing ultimate success in controlling disease.

Responsibility and Impact

Reflects the individual actions that participants express as a cause of liver disease, as well as the predominantly negative self-image associations seen in those with liver disease. The theme “Accountability and blame” explores the predominantly negative actions of negligence that participants associate with disease acquisition, whilst “Image and Agency” considers the negative perceptions and consequences that participants link to those who suffer disease, as well as the wider family in some cases.

Table 11: an overview of the 2 Overarching themes identified in males < 30 yrs

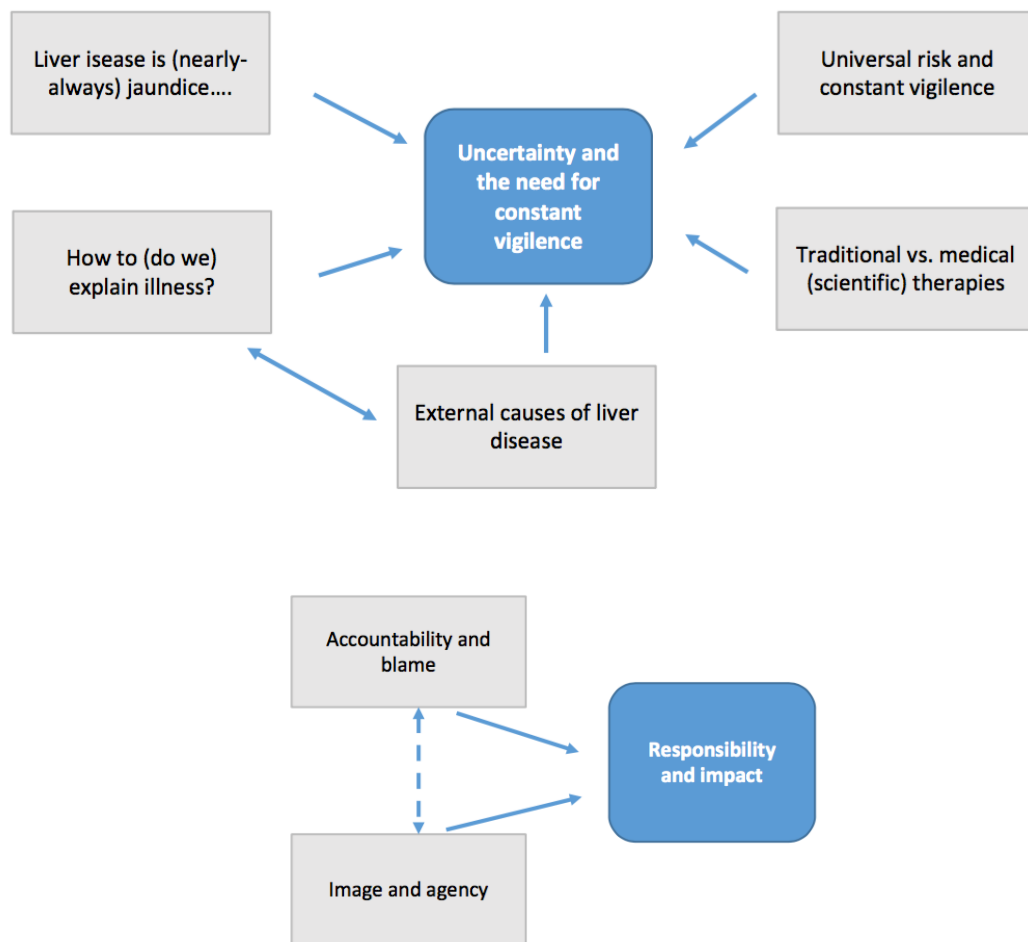


Figure 21: Network map of relations between the 2 overarching themes in males < 30 yrs (“Uncertainty and the need for constant vigilance”, and “Responsibility and Impact”). Bilateral closed and dotted lines represent close relationships between candidate themes.

“Uncertainty and the need for constant vigilance”

Younger male participants seemed well aware of liver disease, but expressed considerable uncertainty in identifying the causes and nature of disease, and in particular how to guard against disease acquisition. Participants identify liver disease principally as jaundice, identifying jaundice as a distinct disease states of multiple causes:

“I heard about it, my friend was infected with jaundice (Participant 1); There are different types of jaundice; one is yellow type and the other is...I heard A and B (Participant 2)”.

Participants conceptualise liver disease as jaundice, with the potential implications of viewing liver disease as only present in symptomatic patients, and the potential needs to expand education regarding the chronic and asymptomatic nature of CVH.

Considerable uncertainty was expressed as to the causes of liver disease in the group, but some participants did express knowledge regarding different types of liver disease, and in these expressions there is also mention that some disease states are more severe than others, and potentially fatal:

“I heard that hepatitis B is very dangerous, and if it becomes worse it can take life, I mean death (participant 2); If get, liver disease is not good. Surely there is the possibility of death (participant 4)”

There is the suggestion that some conditions are worse than others, with the specific mention of HBV in this context. It also suggests that there may be a potential fear for patients to engage with CVH testing, and a role for education in the community.

The candidate theme “how do we explain illness” explores the uncertainty and often conflicting views that are expressed by participants in and how and why disease occurs, and even recurs. Participants conflicted in their opinion of how liver disease occurs, with opposing views expressed:

“...my friend was infected with jaundice. It is not a communicable disease (participant 1); ...It is communicable and transmit easily to others, so need to stay in isolation (participant 2)”

These extracts demonstrate a clear conflict in perception of how disease is caused, and importantly how it is transmitted. It is also of interest to note the language used by participant 1, and the term “infected” to define how his friend was affected with liver disease, and at the same time to consider liver disease to be non-communicable. The views of participant 2 are very different with regard to how disease can be spread between individuals, and is of interest in the ease of disease transmission that he describes, as well as the need to keep those who are infected in isolation, with a potentially profound impact on developing and engaging with community members for testing campaigns. This concept of needing to isolate oneself, also feeds into the candidate themes identified in “universal risks and constant vigilance”, as well as “accountability and blame”, with the need to be on guard to prevent illness, as well as the consequent blame responsibility that acquires if one becomes infected.

External causes of liver disease were expressed by many participants, but with a recognition that even in these traditionally held views, there is an element of uncertainty that they feel in explaining these (largely food based) relationship:

“Water is the main... In Nepal water is the main cause of hepatitis (participant 5)”; *“.....It is due to food...because of not taking care in their food habit it occurs (participant 2)”*

“If you do not care and careful while taking food, the disease likely to get reoccurrence, is that true?” (participant 6)

Food and water sources are widely cited as causative risks for liver disease, and also uncertainties about these risks, and re-acquisition risks that may be outside their control.

Water is expressed as a strong sentiment as the leading cause of liver disease, but with food and in particular “food habits” appearing as an equally prominent feature across the focus group discussion. On the one hand, this may fit with the lived-experiences of community members growing up in Nepal, where Hepatitis A (HAV) is endemic, with faeco-oral contaminated water and food being the mode of transmission [Jacobsen KH 2009].

Alcohol is addressed in discussions, but largely as a possible cause of disease (participant 5) with some expressing no association to jaundice (participant 4); and with food expressed as the predominant cause for disease when participants were asked directly about the relation between alcohol and liver disease (participant 2):

“Umm....you should not take alcohol and local beer... (participant 5); I think, in my opinion, I do not believe drinking alcohol and local beer cause the jaundice. Person rather dies but without jaundice (participant 4); It does not matter the age. It is due to food (participant 2)”

As such, alcohol seems to feature as a low level association with liver disease, suggesting a lack of understanding, or perhaps acceptance of the place alcohol holds in relation to liver disease; particularly in their new home in the UK.

During these discussions the moderator probed participants to ask about possible relations of liver disease with ghost or spirit invasion:

“Yes, I’ve heard! (about) this (participant 3); I’ve also heard about this jaundice. If it is in women, new born baby also gets jaundice (participant 1)”

Here participant 3 enthusiastically expresses his awareness of spirit invasion as a possible cause of liver disease with further expansion of spirit invasion that can affect both mother and child, with implications that are further explored in the candidate theme “self-image and agency”. The expressed belief that spirit invasion can cause disease illustrates a significant divergence from medical understanding and practice in the UK, with implications that may be effect healthcare engagement, management and disease prevention.

Traditional therapy approaches are raised during discussions, with herbal therapies and specific food and drink approaches raised:

“papaya and lots of water! Sugarcane juice is said to be best (participant 4)”

During specific probing, participants recounted their beliefs and experiences on faith-healers and witch doctors in treating disease:

“It did not work for me. I believed it in the beginning.....but, not for me (participant 1); No, it did not work [...] one time I went to the faith healer. At last, I went to hospital. I got better within 2-3 weeks. One time an old man asked me if I am from Nepal. When I nod my head, he asked me if I know some spiritual preacher (healer)? I did not know anybody, so I referred him to the hospital (participant 2) (– followed by laughter amongst the group)”

These extracts highlight the role that traditional therapies still hold, but also an expression that Western or modern medical strategies offer the potential for treatment, even if these strategies are not viewed as separate or mutually exclusive to these traditional approaches.

There is overall an expression that treatment can restore health, and that there is an importance in seeking treatment:

“[...] Surely there is a possibility of death. So that it is necessary to do treatment and prevention activities in time (participant 4); After 2-3 weeks of suffering, I went to see doctor and took medicine and got recovered (participant 2)”

These extracts identify the participants belief that seeking help and treatment is important, and successful, with the aim of detecting disease in time; with potential strengthening of goals to develop healthcare engagement programmes in the community.

Responsibility and Impact:

This overarching theme captures two related candidate themes, and explores the perceptions of the individual as being responsible through their actions for acquiring liver disease, and the predominantly negative impacts that occur as a result.

The candidate theme “accountability and blame” explores the individual responsibility that participants express in preventing disease, as well as the implications that arise in those who develop liver disease:

“[...] It is necessary to take care on food. It is caused by negligence (participant 1); “[...] Because of not taking care in their food habit it occurs (participant 2)”

Participants refer to the need to “take care” at multiple points in the focus group discussion, with a particular emphasis and association placed on the need to control food intake. Participant 1 develops this further, expressing this loss of care as negligence, rather than an accidental event, or temporary

lapse, although as addressed in the candidate themes “how to explain illness” and “universal risk and constant vigilance”, participants also express doubts as to what these risks and agents are, and how one can maintain constant vigilance. Nevertheless, participants seem to express “taking-care” as an important factor in preventing disease, and as responsible for disease acquisition.

This perception of “negligence” as a factor in disease acquisition is echoed by several participants, and is further expanded upon by Participant 3, when recounting a discussion, he had with a friend who had developed jaundice twice:

“Then I thought, he himself not safe, I just kept quite [...]; Ok for the first time he blamed Momo, but the next time I did not know what he ate...? (Laughter) (Participant 3)”

Here, the participant raises a level of discomfort that he feels with his friend in relation to his liver disease. Food and food hygiene is raised as the potential driver of disease and re-infection, with a mistrust in the individual that is suggested.

The theme “Image and Agency” considers how individuals with liver disease are viewed, and shares many of the concepts, such as negligence, explored in the theme “accountability and blame”. Participants generally express a negative perception of disease and self-image in those effected by liver disease, with the concept of “isolation” and separation raised by participant 4:

“...It is communicable and transmit easily to others so need to stay in isolation”

This expression is likely framed by the widespread uncertainty regarding external agents that cause disease, but has implications for how people with infection may be viewed, as well as the potential ability to engage with members of the community who may fear this isolation or segregation as a result of a positive investigation.

The opinions raised during discussions on spirit and ghost invasion raise further considerations on how individuals, and even families with liver disease may be viewed:

“I have also heard about this jaundice. If it is in women, new born baby also get jaundice (participant 1)”

The participant here not only identifies that spirits can cause disease, but that if a mother is affected, or “invaded”; then that the child also suffers from this same invasion. Given the likely, although not expressly stated negative associations of ghost or spirit invasion and disease [Uehara ES 2001], this suggests a perception that the “sins of the mother” can pass onto the (her) child, with broader implications that may apply to families with liver disease.

Issues of agency and support are also addressed in this theme:

“we don’t neglect him. He himself need to cure for his health. It needs to get good treatment. We will guide him in our limited capacity. We have to help him to raise his self-confidence. We need to support and encourage. We have to convince him that the disease will be cured and you will become healthy after treatment (participant 1)”.

This extract demonstrates a strong commitment to support those who are affected, and is positive in its expression not to abandon those individuals with liver disease. A reduced agency is suggested with liver disease, with the ability of individuals to manage illness, as well as the broader aspects of self-management and self-confidence affected by liver disease. Encouragingly there is the recognition that community support is important to improve agency, and that even despite the uncertainties that exist with regard to treatment, that help and advice should be sought.

Questions relating to health education and information in participants identified that Primary Care Physicians were seen as the first port-of-call: *“GP! We go to our GP (participant 3)”*. This supports the needs to understand and develop engagement strategies in primary care.

Summary: The two overarching themes therefore identify the uncertainty that exists among participants in how to explain and guard against liver disease, despite a potentially constant, but unknown disease risk, as well as the predominately negative associations of disease towards those affected.

Awareness of liver disease is clearly stated within the group, with jaundice the defining, if not exclusive feature of disease. Food and water based pollutants are described as the principal driver of disease, with only limited expression of other causes such as CVH. Awareness and knowledge of extrinsic agents such as spirits and witches are discussed, but with the suggestion that these agents are not prominent in the hierarchy of aetiology and cure.

Liver disease is generally conceptualised as a transient and discrete illness, and whilst there is a perception of “negligence” and a “loss of care” associated with liver disease, there is the overall expression within the group to support and encourage those who are affected with liver disease in the community. There is also appreciation within the group to engage with modern medicine, and a strong expression to engage with primary care in particular.

Males over 30:

Three overarching themes were identified through analysis, with an overview of these overarching themes is presented in table 12, and a network map presented in figure 22.

Difficult to spot for the inexperienced:

This overarching theme explores the difficulties that participants present in identifying the onset and causes of disease, as well as the abilities gained through age and experience to recognise and manage liver disease.

The candidate theme “Systemic and Insidious” explores the unpredictable and often unrecognised onset of liver disease, and the perception that age and experience can help facilitate this identification. The theme “internal and external causes of disease” explores the multiple, conflicting causes of disease that participants express from both internal and external agents. The theme “knowledge is power” looks at the conflicts and uncertainty that exist in the causes of disease, as well as the role and desired place of education and experience in understanding and managing liver disease.

Negligence and the loss of (Nepali) traditions:

This overarching theme explores the perceptions of individual accountability in disease acquisition, as well as the ideas that a loss of traditional knowledge and practices has contributed towards liver disease.

The candidate theme “Negligence and blame” explores the perceptions that unclean practices contribute towards disease, as well as the perceptions expressed towards those individuals with liver disease. The theme “Loss of traditions and traditional knowledge” explores the ideas that the Nepali community have lost touch and disregarded traditions relating to methods of lifestyle and cooking, thereby exposing themselves to disease through this abandonment.

Modern medicine is ineffective:

Explores the belief and perceptions that modern (Western) medicine is ineffective in treating liver disease, and the cited experiences of using traditional methods to cure disease, and the belief in these alternative herbal and spiritual methods of cure.

Table 12: A summary of the 3 overarching themes identified from focus group discussions in Male Nepali participants over 30 years

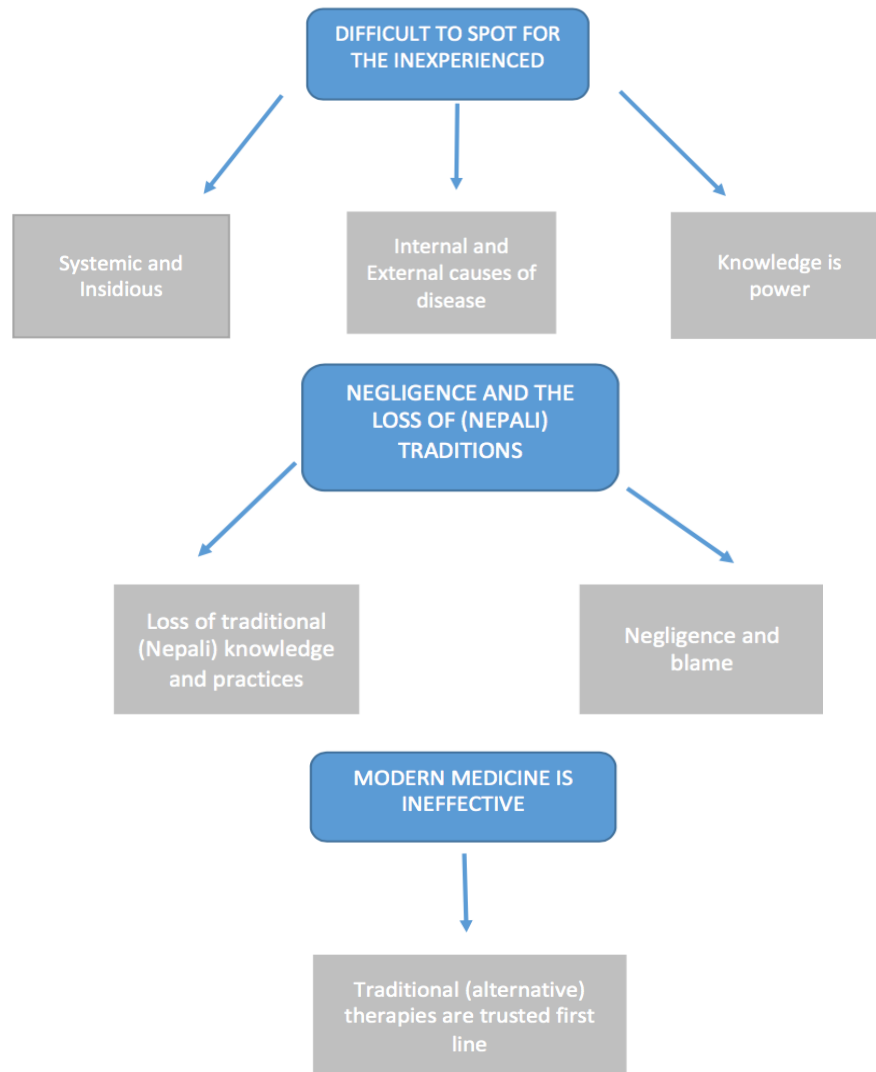


Figure 22: The 3 overarching themes identified from the focus group analysis in Nepali males over 30 years, and the principal candidate themes

Difficult to spot for inexperienced:

An overarching theme that includes three related candidate themes: “Internal and external causes of disease”, “(liver disease is) Systemic and insidious” and “Knowledge if power”, exploring the concept that multiple agents may be responsible for liver disease; and that recognising and managing disease requires knowledge and personal experience.

Internal and external causes of disease:

Participants associate multiple individual (internal) and external driving factors towards disease. The mechanism(s) of these associations is rarely apparent, and despite often conflicting opinions in the

group, there is conviction and certainty in these associations, which are often related in terms of personal or first-hand experience.

Food and water are again commonly expressed as a cause for disease, with additional recognition of particular food groups which cause or perhaps contribute towards liver disease:

“Due to polluted water, the most is polluted food [Participant 2]”, “It is a communicable disease [...], it is not good to eat sour food during jaundice [Participant 3]”, “the most important is food [...] hot pepper and spices are no good [Participant 5]”

Certain foods are confidently identified here with negative properties to exacerbate illness. The suggestion is that these “sour” agents may act to worsen disease even in the face of an alternative communicable cause, identifying these foods as complex and almost dangerous agents that have intrinsic risks, which may go beyond a causative role. There is also the suggestion in these discussions that knowledge regarding these dangerous food groups has declined; an idea that is expanded further in the overarching theme “Negligence and the loss of (Nepali) traditions”.

Participants express many other potential, and often conflicting causes of liver disease that relate to the individual, or actions of the individual, as well as external factors. This includes an awareness of viral aetiologies of disease:

“In my opinion, this disease come from a virus [...] In my knowledge it has been named A, B, C. The really bad one is hepatitis C. It got transmitted blood and blood products [Participant 3]”

This is one of the few instances during all four focus groups where different viral aetiologies are specifically mentioned, and whilst there is little further expression to explore the depth of this understanding, it is interesting to note that the same participant expresses plurality in identifying particular “sour food” agents with these specific and quite detailed viral description:

“It is communicable disease. B and C hepatitis are very serious type. At that time we need to avoid alcohol. The awareness is lacking there. It is not good to eat sour food during jaundice (Participant 3)”

The transmissible nature of liver disease is expressed by several participants, but with conflicting or multiple views expressed by the same individual, as well as within the group:

“Yes, liver disease is a contagious disease; It is communicable disease (Participant 3)”

However, other expressions suggest a more holistic approach to the causes of liver disease that may relate to the individual:

“It might happen from the breakdown of our body system (Participant 3); Liver can be damaged if diabetes gone to complication (Participant 6); Jaundice come out from our blood (Participant 7)”

These ideas are often expressed within broader, and often conflicting discussions, but identify a concept that liver disease can be related to the wider health status of the individual, including the experiences of participants with other health conditions, such as Diabetes Mellitus.

Alcohol is portrayed by several participants as an important agent in liver disease:

“[...] Due to poor knowledge of alcohol it might come to people (Participant 6); Alcohol makes the liver disease (Participant 4); [...] B and C hepatitis are very serious type. At that time we need to avoid alcohol (Participant 3)”

Alcohol therefore features as a primary agent responsible for liver disease, as well as an agent that may exacerbate disease (like particular food groups), with the suggestion that knowledge regarding the dangers of alcohol are not well understood in the community.

The role of Spirits and Witches/Witch doctors to cause and treat disease is a vivid demonstration of the place of such external agents in liver disease:

“...We did also listen that Witch also kill people [...] In this place our seniors advise us not to eat anything there. They said this because there was “Harital”. When Harital become matured and spoiled it become jaundice. That is said by Witch doctor. These Witch Doctor only has “mantra” which heal jaundice (Participant 7)”

This extract identifies the place of spirits and witches by one of the more senior members of the group. This places disease and disease management to some degree outside of personal control, and therefore external to the individual. But at the same time, there is also the suggestion that the individual can modify the action of spirits and witch doctors through their action and behaviours.

Overall, these extracts identify multiple individual and external agents that can cause or influence disease, with a negative association or action that is mostly linked to liver disease. These ideas often seem conflicting, with traditional beliefs that seem to overlay even (seemingly) high levels of disease knowledge. Throughout these extracts, there is as well the suggestion that these ideas are formed based upon the benefits gained through experience and hindsight, a concept that is explored in the following candidate themes.

Systemic and Insidious:

The second candidate theme “Systemic and Insidious” explores the expressed ideas that liver disease presents with subtle features that may arise without warning, and which may go unrecognized, with accounts that seem to reflect either personal or first-hand recollections that they have experienced and witnessed in Nepal.

Older male participants express liver disease in a vivid and striking fashion, with liver disease identified primarily as jaundice, with symptoms that can be generalized and unpredictable:

“All the white parts of our eyes turned to yellow, if we had worn vest it would all get yellow itself after 3-4 days. These were my first symptoms [...] After few days I became so weak and did not have energy to far, so I went down to Aarughat. There, one Ayurvedic doctor (Baidya) saw me and told he knew the disease I had (Participant 2)”

Here the symptoms of liver disease is expressed as jaundice, as well as systemic weakness and loss of function, with a diagnosis of liver disease established only after consult with an Ayurvedic/Witch doctor; highlighting the insidious perception of disease, and the role of experience which is key in later in discussions by Participant 2 in how disease is identified, and the place of Nepali traditions as a cause of disease and poor management; explored in the candidate theme: “Loss of traditional (Nepali) knowledge and practice”.

The systemic and vague nature perceived nature of liver disease is also expressed by other participants in the group:

“[...] after, I did not know how would be liver disease look like. I wanted to pee and went but did not feel that it came out actually it had all come out. You see when we pee, our private part always get erected, and the urine comes out with force and go little bit farther. When I had Jaundice I did not have such energy. Another symptom I realized was yellow color underneath my tongue (participant 2)”

Here the participant describes the onset of jaundice in symptoms that would fall outside most medical practitioners’ radars, and highlights the multi-system and insidious nature that participants associate with liver disease, and the role of experience in identifying disease in these circumstances.

Knowledge is Power

The third candidate theme “Knowledge is power” explores the importance that older participants give towards age and experience in identifying and managing liver disease, and the wish to learn more about the disease process.

This idea is most vividly expressed by Participant 8, after recounting his experience of identifying and managing liver disease in his first-degree relatives:

“Then I learn the medication of jaundice from a Chinese. My wife and son also did had jaundice and the Chinese gave the medicine..... I cured many people.... (Participant 8)”

There is direct importance given to herbal therapies for liver disease here, but also the suggested need and benefit of learning to recognize and treat liver disease, with this learning likely to be relatively unique, but hugely beneficial.

Education levels in older participants is described as low, and participants express the wish to learn more about liver disease, with the (correct) recognition that existing education in liver disease is poor across many groups

“[...] overall, There is no education about liver in school. Children do not know about it. So we uneducated people do not know it obviously (Participant 6)”

A keenness to engage is readily apparent in the focus group, with a wish in the group to learn more about liver disease, and how to manage liver disease:

“we would like to know that what does affect the liver? We want to learn about it (Participant 4)”

“We do not know English so we need in Nepali.....laughing (Participant 4); Literate can use newspaper and such things but illiterate need video programme and video programme is effective to illiterate people (Participant 1)”

A low baseline educational status is again suggested, with the additional suggestion that some may remain unable to engage with written Nepalese media, and therefore reliant on other advertising media such as radio and TV.

Negligence and the loss of (Nepali) traditions:

This overarching theme explores participants’ perceptions towards those with liver disease, as well as the perceived place of traditional knowledge and practice in disease aetiology and management.

The causes of liver disease explored by participants are often expressed in relation to a loss of care, or negative actions by the individual. The perceived role of food and water provides such an example:

“When we see the jaundice from a Nepalese perspective, it is transmitted through stool, urine and food [Participant 3]”

This extract identifies the important place that food-borne transmission routes holds in the Nepali mindset, and in translating perceived causes of disease from Nepal to the UK. It also associates food-borne transmission to actions of diminished hygiene, either through a loss of self-care or poor living standards.

When asked how they would view and treat individuals with liver disease, participants responded to identify a graded stigmatization response, as well as first-hand negative experiences within the group:

“I do not think people hate the person. Yes, liver diseases is contagious disease, it would not be considered as big as leprosy disease. I do not think we have hated jaundice person so much (Participant 3)”

Here, the participant uses the word “hate” in direct response to the moderators questioning, and one hand is reassuring in his expression not to “hate (the) jaundice person so much”, but clearly identifies a separation and likely segregation in how individuals with liver disease are seen, particularly with his very visual reference to the use of Leprosy in stigmatizing those with liver disease.

Following this extract, and with further prompting for other opinions by the moderator, Participant 7 provides a more personal reflection of experiences in the community:

“I do not think this is communicable disease. My brother had jaundice at the age of 6-7 years. He would not drink milk. He use to have porridge (Maize/ wheat). So Jaundice can be caught by children who do not drink alcohol. I thought my brother might have drunk water from dirty tap. People would say it might be because of his mother who drank and that affected the son. But I have also seen the people who had not drunk at all and they had jaundice (Participant 7)”

In this extract, Participant 7 identifies the perceptions faced by members of the community to the role of alcohol in causing liver disease. The blame attributed to the mother in causing disease to her child is again suggestive of a concept where the “sins of the mother” is seen as a possible cause for disease, with potential implications for healthcare engagement in a potentially vulnerable group of individuals.

The second candidate theme “Loss of traditional (Nepali) knowledge and practices” builds upon this to explore the perception that a loss of knowledge and appreciation for traditional and cultural practices risks liver disease, as well as poorer treatment options and outcomes.

Food is again mentioned as a risk and direct cause for liver disease, with several participants expressing a loss in traditional cooking practices, and produce availability that seem contributory to liver disease:

“The most important is food. Instead of mustard oil people are taking different kinds of oil which are heavily polluted....; We say food grains, water and rice. The mixed different rice for making it cheaper price. This is popular in Nepal (Participant 5)”

The same concept is expressed by several participants, and identifies a lack of knowledge, or abandonment of traditional practices to newer methods of cooking with oils and grains that expose individuals to the risks of “polluted foods” that can cause or contribute to disease. The expression that the use of mixed rice is both cheaper and popular also suggests a generational gap with younger members of the community adopting new and risky practices, taking chance with cheaper produce.

Modern medicine is ineffective:

The overarching theme “Modern medicine is ineffective” explores the perception by many in the group that modern medicine offers an inferior approach and efficacy to the treatment of liver disease.

Traditional cures are valued, and a loss in traditional knowledge is explored by Participant 8 in recollecting his experiences in treating members of his own family with liver disease using herbal (traditional) treatments:

“[...] Then I learn the medication of jaundice from a Chinese..... Chinese sold this medicine in \$5 for a cup. This is called Batulejhar (A typical tropical herb). This plant can be found in Kathmandu Nepal. It is available freely in village of Nepal. First of all, we have to wash this plant with hot water and grinding and give to patient. I cured many people (Participant 8)”

During this extract the participant recollects his journey to identify a treatment for liver disease after having lost his mother to liver disease in the past, before discovering a treatment sold to him by a Chinese provider. One presumes this to be an alternate practitioner of traditional of Chinese medicine, and his subsequent discovery the agent sold to him is a herb that is freely available to him in Nepal, suggesting a traditional knowledge that has been lost or neglected by the Nepali community.

The same participant then goes on to extol in vivid detail the positive benefits of this knowledge, and the place of traditional therapies in managing liver disease:

“[...] My mother died from jaundice. She died in hospital after operation in British Army Camp Dharan Nepal. Then I learn the medication of jaundice from a Chinese. My wife and son also did had jaundice and the Chinese gave the medicine [...] I cured many people. Some died but

many people cured from my treatment [...] Doctor takes 2- 3 moths to cure but this treatment cured within 2-3 days (Participant 8)”

Here, Participant 8 explores the failed treatment achieved in the British camp, taken as the best access point for modern medicine, as well as the personal positive experiences gained within his own family and the relative success seen replicating this with many other members of the community. He also describes later the fast efficacy of cure in comparison to (unspecified) modern medical approaches, as well as a broad range of mental and physical benefits that can be achieved with these herbal approaches.

This idea is also supported by Participant 2 in discussing his route to treatment through Ayurvedic therapy:

“There, one Ayurvedic doctor (Baidya) saw me and told he knew the disease I had. So he suggested me not to go for further checkup. He persuaded me to treat well by giving the herbal medicines [...] It was difficult to get sugarcane and was off season for papaya. Anyhow I searched for papaya and sugarcane juice elsewhere. That Ayurvedic medicine helped to treat me. Some people at that time had told me jaundice would reappear but till now I am fine (Participant 2)”

Here, the Participant describes his positive and successful experiences of treatment through traditional therapies, but it is interesting to note the reassurance provided and perhaps requested by the participant in “persuading” him to commit to Ayurvedic therapy, and the commitment involved in searching out off-season treatment ingredients. It does nevertheless suggest the perceived role for traditional health-providers as the first port of call in illness.

Traditional Witch doctors are also discussed as agents who can modify disease:

“These witch Doctor only has “mantra” which heal jaundice. There was many story where Witch Doctor treated jaundice. Modern medicine and injections are really bad for jaundice. I have seen even a British army officer in Dharan Nepal went to treat his jaundice with that witch Doctor and he was completely cured (Participant 7)”

These Witch doctors are portrayed as having significant and unique power to treat disease, as well as a broad expression that these abilities surpass conventional medical treatments, with the gold-standard example of a British Officer choosing to use these alternative therapies, and being successfully treated over Modern-medical therapies for his jaundice, providing a strongly worded personal opinion on the place of traditional therapies in liver disease.

There is little counter to these expressions during focus group discussions and overall there is a sentiment that liver disease assessment and treatment is best provided through traditional (alternative) healthcare providers and therapies.

Summary:

Awareness of liver disease seems strong in the group, with vivid recollections of personal experiences associated to liver disease. Whilst there is uncertainty again as to the causes of disease, there is a great deal of certainty expressed for a heterogeneous list of agents linked to liver disease, with food and cooking practices the most strongly expressed agents.

Disease is understood as a severe condition, that is difficult to identify and manage, with age and experience expressed as a positive force to help in disease identification and management in the community. Perceptions of stigma are expressed, with liver disease associated to a loss of traditional practices, as well as possible association to food hygiene standards. Personal actions and responsibilities are also expressed through the external role of spirits and witch doctors in causing disease.

Several participants discuss the futile efforts seen with standard medical approaches in Nepal in the past, and herbal and traditional therapies are strongly mentioned within the group. Although there is a negative perception that is implied towards those with liver disease, this is within the concept of most participants who discuss their own first-hand or personal experiences of jaundice and liver disease, and it is likely that the group would remain supportive to other members of the community who may be affected.

Female participants less than 30 years:

Three overarching themes were identified from the focus group of female participants less than 30 years: (Liver disease has) “Many names and many conflicting causes”, “Bad people and bad practices”, and “Modern versus traditional therapies”. These themes are summarised in table 13, with a network map presented in figure 23 below.

Many names and many causes:

This overarching theme explores the different expressions within the group regarding the causes of liver disease, with the identification of multiple perceived routes of disease onset and acquisition, but with often conflicting opinions raised within the group.

Bad practices and bad people:

Here, the predominantly negative associations of liver disease, and perceptions of bad (lifestyle) practices leading to disease are explored.

Modern versus Traditional therapies:

In this overarching theme, the perception of participants towards treatment is explored. Participants express little first-hand experience of liver disease; expressing on one-hand quite detailed knowledge of modern medical treatment options for liver disease, whilst also expressing strongly held, and conflicting views on the role of traditional (alternate) therapies in managing liver disease.

Table 13: summary of overarching themes from focus group exploring perceptions of liver disease in Nepali female participants < 30 years

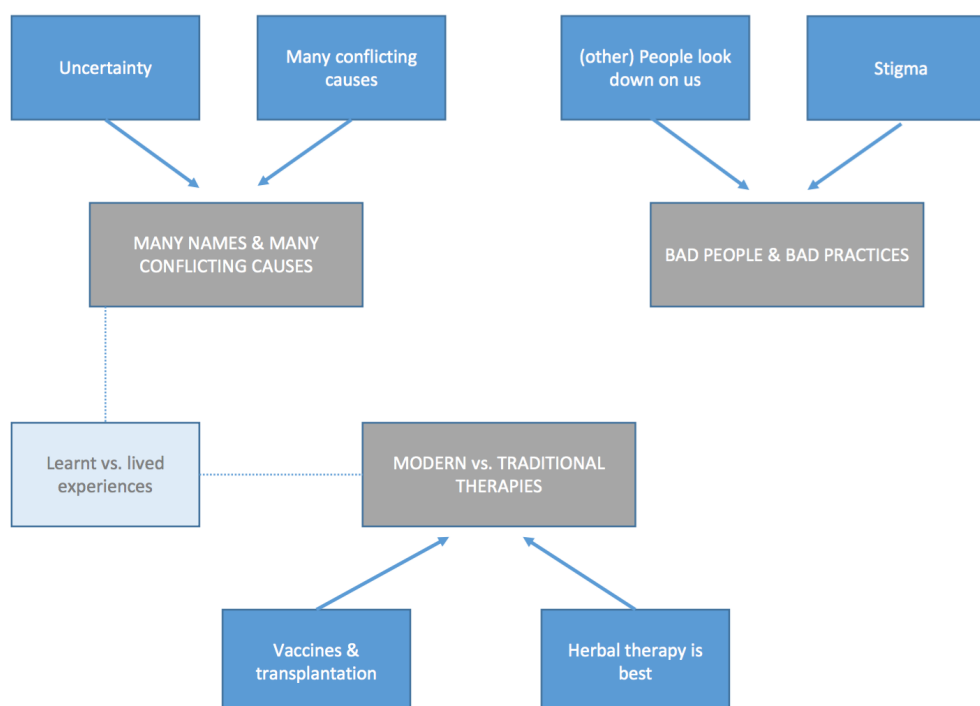


Figure 23: network map of overarching themes, and relation to key candidate themes

Many names and many causes:

This overarching theme explores the many different associations that participants express in describing liver disease, and its potential causes or contributing factors.

Younger female participants in this focus group are the only group not to express any personal or first-hand experience of liver disease, and there is a wide range of opinions relating to the possible drivers of liver disease, with often conflicting viewpoints.

A communicable or hereditary nature for developing liver disease is one such conflicting viewpoint, with participants expressing opposing views:

“No, it is not communicable in my opinion (Participant 1); Hereditary, genetic, Diabetes and foreign country are also risk factors (Participant 5); Genetic, not communicable (Participant 3)”

These expressions are among the first responses to the moderators probing regarding the possible causes of liver disease, and if a communicable cause could be responsible. They identify quite strong set opinions suggesting an inherited, or intrinsic risk for liver disease, with a genetic cause specifically mentioned by two participants. Participant 5 also identifies Diabetes, and therefore other systemic disease processes that may contribute towards liver disease, and identifies foreign nationality as a possible risk factor disease. This latter point is not expanded on, or commented upon further here by other participants. As such, the understanding and belief related to this “foreign country” association is difficult to unravel here, and potential associations and reflections towards risk in different nationalities is discussed in more detail in the following section.

Communicable causes of liver disease are addressed by several participants, raising potentially infective and non-infective drivers of disease:

“It might goes from one person to another person. It depend on what kind of liver disease it is. I have read in book and it is written that liver disease is a communicable disease (Participant 4)”.

Infectious causes of disease are also discussed by some participants as potential causes and transmission routes:

“Contacting with liver patient is the main factor for spreading disease to others (Participant 1); [...] It might transmit, it is an infectious disease by nature (Participant 5)”

The two participants here identify possible routes of transmission through personal contact, with the potential impact on contact and isolation. The level of certainty in these expressions though is variable, with further expansion of this theme in the following sections.

External causes of disease are again suggested, with pollutant factors from environmental sources:

“Smoke, dust, air and water are the source of infection. It is a matter of lifestyle..... (Participant 6)”.

Here, there is mention of a wide range of potential agents that may act as direct drivers, or carriers to cause and transmit disease, with the additional association of personal action and responsibility that may lead to disease. It is of interest to note though, that the strength of these associations is less than the role placed on food and water borne transmission routes in other focus group discussions.

Spiritual associations towards liver disease are explored by two participants, although only after direct probing by the moderator on the role of these factors in liver disease:

“Witch person can also give the disease. People says, previous life sin also responsible for this disease (Participant 2); Spirit also invade people resulting in liver disease, people says so [....] (Participant 1)”

Spiritual and traditional associations to disease are mentioned late on in focus group discussions, and both participants frame their expressions as reflective of other peoples, or the wider community perception. However, despite this, it is likely that these perceptions still hold relevance to how people with liver disease are seen; and the importance placed on alternative and herbal therapies (discussed in the overarching theme Modern versus traditional therapies) highlights that traditional perceptions hold perhaps a greater position than initially suggested in these expressions.

The overall uncertainty raised by participants through these multiple and conflicting potential aetiologies is also apparent in participants efforts to define and describe liver disease:

“It might be many names. Different stage might have different names. I do not know much about it. I know only liver disease. Liver cancer is one which I know.” (Participant 5)

Here the participant identifies a potential heterogeneity that exists within the term “liver disease”, as well as their own knowledge gaps in defining this. Liver cancer is suggested as the most memorable type of disease, with an implied severity and importance, but perhaps also a level of potential futility associated with disease.

Similar expressions are also put forward by other participants, with a broad range of potential drivers and potentially different types of liver disease that can occur:

“[...] There are many.....liver cancer and hepatitis A B C D etc. It can be prevented through immunisation.” (Participant 3)

Liver disease is described here again as one of its severe end-stage complications, as well as potentially infective (viral) causes of disease. The participant demonstrates a relatively wide knowledge of these different types disease, but with associations and stigmatisation with these different types of disease that are explored in the following overarching theme “Bad people and bad practices”

Bad People and Bad Practices:

This overarching theme explores the predominantly negative associations of liver disease expressed by participants during focus group discussions.

When asked their perceptions about liver disease, and indeed if the moderator would have liver disease; participants demonstrated largely negative associations:

“Not good, it is bad. We think you are alcoholic and smoker so that your get the disease. We suspect about his wrong behaviours. But some time it is bad when good people get infection (Participant 3)”

Here, participant 3 expresses concern about bad practices, with a direct relationship drawn towards those with liver disease; and although she does identify the possibility of “good people” developing liver disease, the overwhelming association seem negative.

Smoking and alcohol are mentioned as specific negative associations by many participants during focus group discussions, with both activities largely mentioned simultaneously, with little differentiation in risk and associations:

“Mainly alcoholics and smokers get the disease (Participant 1)”

Further and more direct negative associations are raised during discussions on the type of people who may get liver disease:

“It does not limit within age and sex. Younger or older young or children and male or female anybody can get liver disease. Alcoholic and prostitutes have more chance to get it (Participant 4)”

On the one hand the participant seems to take a levelled approach on the risks and unpredictability that all groups may face. But the direct and blunt associations to “alcoholics and prostitutes” identifies clear stigmatisation towards those affected by liver disease.

Other participants also express similar negative associations towards the profile of patients who may develop liver disease:

“It is high chance of getting liver disease who live in unhygienic environment (Participant 2)”

This association again raises the concern of stigmatisation towards those with liver disease; with concern also regarding how individuals are seen in the community:

“Contacting with liver patient is the main factor for spreading disease to others (Participant 1)”

Although this expression is a solitary comment, it does further raise the concern that individuals with liver disease may be treated differently with the risks of isolation, and separation from community links.

Negative associations of disease are also identified when participants were asked their perception of liver disease between the Nepali, English and Chinese communities:

“I think more English and Chinese people have it than Nepali. They use more perfume and take less shower. They smell badly. They point to us but I say we are more healthy then them. I felt they are neglecting us. Laughing ha..... (Participant 2)”

The overall expression here is playful, but there is the clear suggestion that liver disease is a negative issue, which communities would not want to be associated with. There is also the interesting identification that members of the community feel themselves separate to, and looked down upon by members of the English and Chinese communities.

Modern versus Traditional treatment strategies:

This overarching theme explores the perception of participants towards treatments for liver disease, with conflicting views expressed between the place of modern medicine and traditional therapies.

On the one hand, participants responded to questioning regarding outcomes in liver disease with positive and detailed treatment options:

“it might be recovered in first stage of disease (Participant 4)”

“why not this is a liver transplant age; transplant like kidney. Diet management, exercise alcohol etc. (Participant 5)”

Here the participants identify that liver disease may produce variable outcomes, with early disease that may even recover on its own. In addition, Participant 5 explores the quite complex considerations of transplantation in liver disease, as well as the more holistic options that one can employ in managing liver disease. Transplant considerations are not explored in further detail, and given the absence of first-hand contact with liver disease patients in the group; one presumes this knowledge has been gained through (health) work or study practice.

Expressions from other participants' though associate a more pessimistic outlook with regard to liver disease, and identify treatments that are best served through traditional methods:

"If we get it herbal remedies are very good. The English modern medicine is necessary to take regularly. But herbal medicine cure slowly. When recovered it is not necessary to take again and again. It is said that herbal medicine is best but it does not cure the disease completely (Participant 3)"

"Get cured by herbal medicine. I heard. I think ayurvedic medicine is best (Participant 2)"

These extracts demonstrate a confident expression regarding the benefits of herbal therapies in liver disease, including its' direct benefit over modern medical approaches; despite the possibility that these herbal therapies may "not cure the disease completely".

Some opposition to this view is expressed, but with the benefits of ayuverdic treatment reduced, rather than discounted:

"I do not believe in ayurvedic medicine. Why so I do not know. This medicine does not cure any disease. It helps only to slow down the disease (Participant 5)".

The place of traditional therapies and causative factors are also identified in discussions regarding the role of Spirits in liver disease:

"[...] spirit also invade people resulting in liver disease, people says so. If Spirit support you then the disease is cured (Participant 1)"

Here, Spirits are identified as a potential (external) agent that can cause disease, as well as promote cure. The broader concepts relating to the role of Spirits in disease, also suggest an associated towards personal, or even familial action that may have provoked Spirit invasion, and transmission.

Summary:

Younger female participants are the only group to not frame their expressions within first hand contact, or personal experience of liver disease. Awareness of disease seems common place, but there is greater conflict and uncertainty expressed in the knowledge of causative agents associated with liver disease.

Perceptions of stigma are described more strongly, with associations to alcoholism and prostitutes specifically mentioned. However, there is the expression within the group to support those who may be affected, and that liver disease can affect anyone.

There is considerable heterogeneity in treatment options discussed for patients, but with strong expressions of certainty in many of the options discussed, and with traditional therapies endorsed by several participants.

Older Female Participants > 30 years

Older female participants took part in this focus group, with 3 overarching themes that were identified: (liver disease is) “Often too late”, “Control and personal strength” and “The role of advocacy”. An overview is presented in table 14, with a network map summary in figure 24.

<p>Often too late:</p> <p>This overarching theme explores participants’ views and first-hand recollections that liver disease often presents at an advanced stage, and incorporates two candidate themes: “Sudden and insidioua” and “Fatal despite best treatment”.</p> <p>Control and personal strength:</p> <p>This overarching theme explores the perception that inner strength and personal will are necessary and successful measures in combating liver disease.</p> <p>It includes two candidate themes: “Stigma and negative perceptions of disease” and “Control, behaviour and personal strength”, exploring the negative associations that participants express, as well as the importance placed on self-control and personal-strength in modifying disease</p> <p>The role of advocacy:</p> <p>This overarching theme considers the role the participants advocate in promoting agency in those individuals affected by liver disease to seek and achieve help for their liver disease.</p> <p>It includes two candidate themes: “Support the ill”, and “Treatment has moved on”, exploring the groups expression to support and build agency, as well as the overall wish to learn and engage with health treatment strategies that can be gained through modern medicine.</p>

Table 14– overview of themes identified in focus group discussions among elderly female Nepali participants

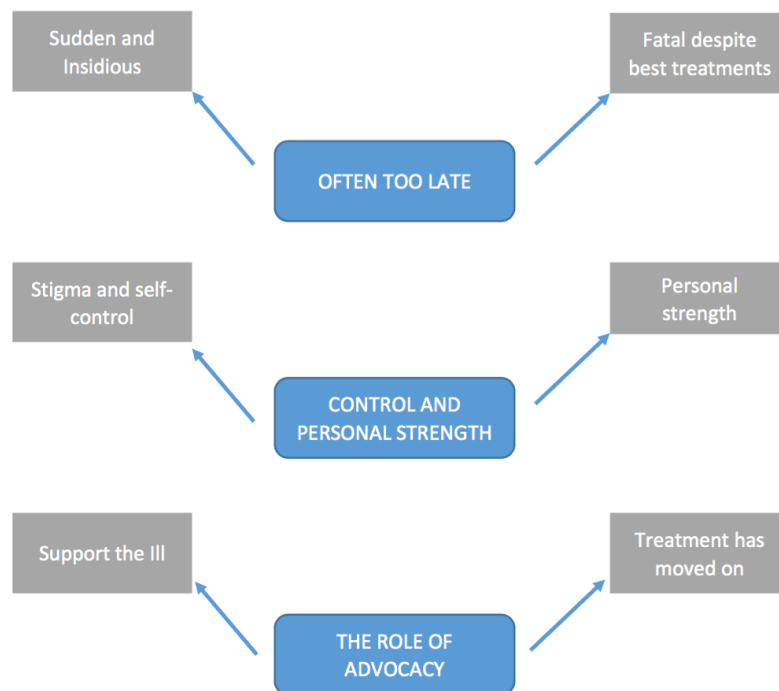


Figure 24. Network Map of relations between Overarching and Candidate themes

Often too late:

Older female participants discuss and describe liver disease principally in the context of witnessed experiences through close-contacts or relatives. Liver disease here is identified as severe, with the overarching theme that it is “Often too late” by the time disease is identified; explored further in the two candidate themes: “Sudden and insidious” and “Fatal despite the best treatment”.

Sudden and Insidious: Several older participants identify liver disease as a condition that presents suddenly, with little or no warning symptoms:

“My uncle had liver cancer. He had sudden pain in stomach. Initially hospital did not find out the problem. Later they discovered that it was cancer. He was died after 2- 3week of cancer diagnosis. That was so sudden (Participant 3)”

“They can be alive and they are dying when told so. My father was died because of that (Participant 7)”

“One person was died during jaundice because of alcohol. He was died on the way during his walk (Participant 1)”

These extracts identify the severity that participants associate towards liver disease through powerful recollections of sudden disease onset in close relatives. It identifies an insidious nature to liver, with even the doctors unable to identify the true liver disease on first presentation (Participant 3). The latter extract from Participant 1 also identifies the striking unpredictability and severity associated to this insidious disease, as well as possible negative associations towards liver disease through alcohol that are discussed in the overarching theme: “Control and personal strength”.

Fatal despite the best treatments: As well as the insidious nature of disease, participants also identify liver disease as a condition that is often “fatal despite the best treatments”.

“Recently, one of our sisters mothers in law’s son died at Frimley Park Hospital due to liver disease. He had operation 16 years ago. Last year December, He went to Nepal. Doctor told him no possibility of life (Participant 1)”

“That my sisters son was always busy in work [...] Finally, they took him hospital and came to know that all is damaged. Anyway, now I heard that liver is finished (Participant 9)”

“My brother had a pain full lump in abdomen which was known in only three to four months advance [...] Doctor told that it was too late. Liver is largely damaged. Operation was performed but not recovered. It was too late (Participant 3)”

In these extracts, participants expand on the insidious nature of disease, identifying a negative outlook for individuals diagnosed with liver disease, even despite seeking medical help. Participants express a level of futility here in these extracts, with medical and surgical interventions that cannot save the individual once liver disease has taken hold. However, it is of note that these personal recollections describe individuals presenting at advanced stages of liver disease, when indeed outcomes are worse; contour to our aims to facilitate early testing, diagnosis and health care intervention.

During focus group discussions, participants identify personal differences in treatment access and outcomes based on social class and location (urban versus village locations), which is discussed in the overarching theme “Treatment has moved on”. However, even in this setting, participants identify a relative futility that extends across this perceived gap:

“Like this many people died in Nepal. Many died with this problem. Even rich people reaching Delhi hospital did not get cure (Participant 1)”

Overall, these extracts identify a negative outlook and futility with regard to a diagnosis of liver disease, with powerful descriptors of first-hand experiences in close relatives, which may have impact on community engagement strategies.

Control and Personal Strength:

This overarching theme considers two candidate themes: “Stigma and negative perceptions of disease”, and “Control, behavior and personal strength”; exploring the perceptions that personal control and action can modify liver disease, despite the presence of negative stigmatizing features.

Stigma and negative perceptions of disease: Associations between liver disease and alcohol and smoking are frequently expressed during discussions, with negative associations towards personal behavior:

“[...] People says heavy smokers and heavy drinkers (alcohol) will get liver disease easily. How does it happen as disease I do not know (Participant 1)”

“There are lot we can see who have problems of live who drink alcohol. I have heard that most of the liver disease person are alcoholic (Participant 5)”

“ [...] Nepalese have poor life style and environment [...]. They do not care about health. The do lots of physical hard work. Carrying lots of weight. When they are tired they drink alcohol (Participant 1)”

These extracts identify the well expressed links between alcohol and liver disease, with smoking seen again as an almost equal disease risk. A failure in personal actions and behaviour are suggested factors here, with the latter extract by Participant 1 identifying the lifestyle difficulties that many Nepali face, and the physical demands and lack of current healthcare engagement and health self-management that are suggested to go hand in hand with ongoing heavy alcohol intake.

Control, behaviour and personal strength: This candidate theme explores the role of personal action in controlling and modifying liver disease:

“[...] From food to all things need to take care. Need to eat only selected food.....Our relative mothers side brother was like this. He used to drink alcohol before. When he was identified as liver patient, he control many things like food. After liver operation he survived almost 16/17 years. That was great for him. Doctor told him that he would not survive more than three months but with his strong determination and meditation he died after six months (Participant 1)”

“Can be cured. If we control ourselves we can survive longer otherwise we have die quicker (Participant 4)”

These extracts identify the multifactorial and holistic approach participants link both to disease aetiology and to its' control. A need for care and caution in nearly all aspects of life is suggested by

participant 1, with an accompanying powerful testimony of the positive action that can be achieved through these measures.

The overall format of these control measures appear heterogenous in participant discussions, and incorporate measures such as alcohol cessation; but more broadly seem linked to a positive mental state, and are represented through positive stories of endeavour and hope, despite ultimately negative outcomes.

The role of advocacy:

This overarching theme explores the views of older female participants that there is a need to build and promote health-seeking agency in members of the Nepali community, with treatment options that offer a greater potential than healthcare opportunities in Nepal; explored through the two candidate themes: “Support the ill” and “Treatment has moved on”.

Support the ill: The importance of seeking healthcare is expressed during discussions, with particular focus placed on the disparity seen traditionally by poorer, isolated members of the community in Nepal:

“It is necessary to get best medical care and medication. Nepal does not such facilities of treating liver diseases. Richer will survive because of better treatment but poorer will die. It is hard and difficult for poor (Participant 1)”

“Nepalese have poor life style and environment. They are very illiterate. I think these are the distinct cause among Nepalese [...] (Participant 1)”

Here, the participant describes the traditional difficulties that certain members of the community face in access to healthcare in Nepal, which may affect the engagement process of these individuals in the UK; with socioeconomically deprived groups whom are conversely more likely to have greater healthcare needs and priority [CSDH 2008, Stringhini S et al. 2017].

Participant 1 also uses the example of a community member that she helps to seek medical help:

“[...] Few days back, in our Aldershot, one old lady always coughing. I helped to take appointment in GP. She told that she had back pain. In GP Doctor told that there are affects in liver. Then she stop smoking and getting better now (Participant 1)”

Here the participant identifies the potential role that members of the community can play in supporting and facilitating healthcare engagement for those who may not be aware of the need or benefits of seeking help, and who may also lack the agency to access services.

Responses within the group towards the moderator being (hypothetically) affected by liver disease also identifies a broader sense of support and agency that exists:

“We need to ask you. How did happen such a beautiful girl. What she had eaten? What made her liver disease? We have to think what makes her good (Participant 5)”

“Must be good perception. Need to give assurance. And need to treat in a right way (Participant 1)”

Here, despite the negative associations that may exist towards liver disease, there is the suggested importance of looking beyond these perceived negatives to provide support and agency to promote wellbeing in the individual, with potential encouragement towards endeavours to improve healthcare engagement.

Treatment has moved on:

Participants provide rich detail in identifying the opportunities and outcomes of treatment in Nepal, with some uncertainty in how to approach healthcare here in the UK:

“[...] In our village sugar cane and papaya is considered as a good medicine. It also cured jaundice but here we do not know what is better for jaundice (Participant 3)”

At the same time, there is strong recognition of the role and importance of healthcare professionals in bridging this gap, and in identifying disease and providing treatment:

“We know the pain but Doctor is the real person to identify the cause of the problem (Participant 3)”

“What the doctor said, we trust on it. Whatever he says. Heart or liver??? We trust him. We do not know more (Participant 2)”

Here, there is a strong desire to engage with healthcare professionals, and a recognition of the lack of ability that individuals may face in trying to diagnose the condition, and in providing effective treatment.

Participants also identify the place of progress and opportunity afforded through modern medicine:

“Now many things has been changed. The world is very much forwarded. There are lot of advance technology to diagnose and treat the disease. It was not like this earlier. People did not know about their disease in the past.... (Participant 1)”.

These expressions suggest a positive change that participants see in healthcare opportunities in UK, with potential encouragement for community healthcare engagement strategies

Traditional healthcare approaches, with the role of Witch doctors and Spirits are also discussed by participants, but typically to frame these approaches within the context of older treatment choices in Nepal:

“ha..... No it does not happen liver disease with spirit invasion. I do not believe on this. If the person is physically look healthy the people say spirit invasion. We also say so in earlier. Now a day’s people go to doctor when they are sick (Participant 4)”

“Take to witch Doctor. There is one disease. He asked to kill the chicken, goat. Time pass patient died (Participant 4)”

“People did not know about their disease in the past. Now a day’s also people died who live in rural areas. They do not know the cause of death. They might died from heart disease or liver disease who knows?” (Participant 1)

The two participants here place little relevance to the role of these treatment approaches in the modern day, with a lack of understanding towards disease and modern treatment options, portrayed as a reason behind the attractiveness of these strategies. However, Participant 1 also suggests during these discussions that members of the rural community in Nepal still face difficulties with knowledge and access to healthcare that may still keep these approaches attractive and relevant to some groups despite the overall group consensus to embrace the options afforded through access to modern medical healthcare.

Summary:

Awareness of disease is strong in the group, with older female participants providing vivid first-hand accounts of liver disease. There is heterogeneity in the potential risks factors associated with disease and with specific aetiological agents, with the perception that liver disease is often a severe and even futile condition, and one that should be feared.

Negative perceptions and potential stigmatising factors are discussed, with additional weight and association given to the need and role of self-control and responsibility in protecting and controlling liver disease.

The concept that “treatment has moved on” is identified within the overarching theme of “advocacy” to support the community to embrace new therapies in the UK that many would not have received or been able to access in Nepal, with health perceptions and interactions in Nepal that may have been negatively influenced by wider inequalities that exist for some (mostly poor) individuals in Nepal.

Chapter 5

CVH testing in Primary Care: Exploring the awareness, knowledge and perception of CVH testing in Migrant Communities

Chapter 5: CVH testing in Primary Care: Exploring the awareness, knowledge and perception of CVH testing in Migrant Communities

Chapter Summary

Primary care forms the bedrock of NHS services, with the vast majority of NHS patient interactions occurring with General Practitioners [NHS England March 2017]. It is the first port of contact for patients, providing access to care, as well as coordinating and commissioning care to patients in the UK.

The involvement of primary care is crucial in improving testing access and engagement in hard to reach and marginalised communities, who may otherwise be left isolated and exposed to the development of advanced complications from untreated disease states.

Context

Primary care has traditionally acted as the gatekeeper for all non-emergency NHS interactions, with close to 300 million patient interactions per year [King's Fund 2009]. GPs initially acted as independent contractors in the NHS, until contract re-negotiations in 2004 when they were contracted through practices to the local PCT. The 2004 contract also led to the introduction of Pay for Performance (Quality and Outcome Frameworks (QOF)), providing a points based rewards incentive to practices for achieving targets in certain clinical and non-clinical service settings [King's Fund 2009], although without viral hepatitis managing to be included as a QOF indicator despite its advocacy by many leading professionals, including the Lancet commission [Williams 2014].

For many years GPs were widely derided by politicians and many in the media for being overpaid following these contract re-negotiations [Times May 2014], and it is only over the past few years that politicians have begun to recognise the increased demand that GPs have been facing with chronically reduced funding, and now a perilous situation with GP recruitment in many parts of the country [Guardian 2014].

Indeed, politically this increased demand and chronic underfunding was nationally recognised in the 5 Year Forward View (5YFV), and subsequent General Practice Forward View created in August 2016 [NHS England October 2014, NHS England April 2016], with plans for increased funding, resources and staff recruitment by 2020. However, ongoing vacancies persist in a disproportionate manner in many parts of the country, coupled with excessive service demands that have led to a significant drop in staff morale [Pulse April 2017, Pulse November 2016].

The future shape and character of primary care services also face considerable uncertainties, with pressures to integrate health services lying at the heart of the powerful 5YFV and the 2017 5YFV review documents [NHS England 2014, NHS England March 2017]. Models of integration are being trialled across the country, including in selected Vanguard centres between multidisciplinary

specialties [NHS England Sept 2016], but with the successful outcome, and implications for primary care working practice that will remain unknown for some time. Recent reviews have also raised doubts over the merit and need of QOF points, which have received criticism for their cost and limited direct evidence for clinical effectiveness in improving patient outcomes [King's Fund 2011, BMJ August 2016, NHS England March 2017]. QOF points are likely to be disbanded given these concerns [NHS England March 2017], and a replacement for this scheme has not yet been made clear, with further uncertainties in working practice that may result.

Despite though these pressures and increasing workload, primary care continues to enjoy some of the highest satisfaction levels seen in the NHS, with recent public support levels of 85% [NHS England March 2017], and proven efficacy in delivering clinically effective holistic care.

Primary care testing in migrant communities - Literature review and need for study:

Migrant groups can be considered as “hard to reach” groups, with differences in health seeking behaviour, and concerns relating to inequalities in healthcare access, and needless disease progression and healthcare costs [Flanagan SM]. A multidisciplinary range of factors are likely to influence access to healthcare, and these have previously been suggested to involve: legal entitlement, knowledge and awareness of the health system in a new country, previous experience of health care, language and cultural barriers, health beliefs and attitudes, and the existing health system configuration [O'Donnell CA et al. July 2015].

Primary care is the main access to healthcare in the NHS, and can act as the gateway and coordinator for migrant health [O'Donnell CA et al. July 2015, RCGP 2013]. GPs have a responsibility to provide healthcare to all those seeking it, including asylum seekers, refugees and other migrant groups, with care that is provided without charge, and practices cannot refuse registration to migrants whilst continuing to register British citizens [RCGP 2013, BMJ 2012]. In secondary care some NHS services, including emergency services in A&E are free to all, but with charges that then depend again on the health condition, residency status, and health surcharges that has recently been introduced for some migrant groups [DoH 2017] Department of Health (DoH), Guidance on implementing the overseas visitor charging regulation, October 2017]. Whilst patients can continue diagnostic and management interventions in a secondary care environment, these are designed to manage advanced, or specialist cases, where a greater financial cost is likely to be evident, as well as morbidity impact to these individuals [BMJ 2012].

Primary care is widely cited as a desirable and effective intervention in migrant health, with improved health outcomes and long-term cost savings that can be achieved through effective interactions and early interventions in migrant communities [O'Donnell CA et al. 2015, Montesi L et al 2015, NICE 2012].

However, concerns exist regarding the practice and efficacy of such primary care interactions, with criticisms raised even in common and well understood disease states such as Diabetes and Cardiovascular disease, where the healthcare consequences (and costs) of failed interventions are better studied, and with higher rates of non-communicable diseases that are higher, and may increase over time in migrant communities [Norredam M, October 2013]. Lower consultation times with migrants, as well as lower levels of non-verbal empathy during discussions have been demonstrated in studies in primary care, as have detrimental variations in prescribing habits that have been documented by primary care physicians across well-developed health systems in Europe and Australia [Montesi L et al. 2015].

The Second Translational Gap and Clinical Inertia

Variations in practice exist despite often well published evidence-based practice guidelines, with these guidelines now a common feature across healthcare, including in primary care. However, the translation of guidelines into practice is not always achieved, which remains a problem in all patient groups, including migrant communities. This “second translational gap” was first identified in studies into the context of the UK Health Research Strategy by Cooksey in 2006 [Cooksey D 2006], with complex multi-factorial characteristics that are likely to drive and effect this translational gap. In primary care, considerations include the relatively unique research and implementation culture that exists in primary care, as well as the individual variations that exist in the make-up and context of independent primary care teams across the country [Lau R 2014].

Another concept that explores this gap is Clinical Inertia, looking at principally the clinician related factors that impact the benefits and harms that are seen towards treatment, and treatment escalation [Khunti K 2013]. These clinician-related factors are well illustrated as a mixture of three linked problems in the management of chronic diseases: the use of “soft” reasons to not escalate therapy appropriately; an overestimation of the current levels of care provided, and a lack of education and training [Phillips LS 2001, Salisbury C 2006]. Clinical inertia is defined principally in non-communicable disease states such as diabetes and hypertension, with effective treatment escalation a key consideration. Diagnostic inertia is a related concept, that focuses more on clinicians’ non-adherence to clinical guidelines in diagnosing disease [Martinez-St John DRJ 2015]. Whilst all these concepts are described almost exclusively in non-communicable disease states, they are of interest in the considerations they give towards clinicians’ attitudes and knowledge towards guidelines, and their awareness and perception towards patients’ attitudes in their clinical actions, which is of particular relevance in the study of CVH testing activity in primary care [Martinez-St John DRJ 2015]. Developing qualitative studies in primary care is therefore important to understand these factors, and to assess the potential areas to develop and target future interventions.

CVH testing in primary care

There is no official measure of CVH testing practice or testing indication in primary care, and data that I collected from regional laboratory data in Surrey, would suggest that most CVH requests are put forward in the context of deranged liver function tests or established liver disease, with 1328 out of 3458 (38%) testing requests in “symptomatic” cases, compared to 11% (380) of requests which would be in keeping with conventional case-finding criteria [Appendix page 273]. This data is supported by studies of HBV testing for migrant communities in primary care, with only around 12% of an estimated 82,651 migrants receiving HBV testing across 8 GP practices, with 75% of these individuals being female, and antenatal testing therefore taking the leading role in testing rationale [Evlampidou 2016].

GPs are thought to offer CVH testing principally as part of individual choice and experience, with variation in testing practice that was demonstrated by Bechini et al. across European countries, as well as variation within nations [Bechini A 2012]. This variation seems linked to individual or regional experience and preferences, and the same study also demonstrates lower rates of CVH testing offers to migrant groups in the UK in comparison to other European countries in primary care [Bechini A 2012].

Testing activity and success will also depend on the health interaction by migrant communities, with differences in healthcare engagement practices that are known to differ in some migrant communities [Kessing L 2013], and with lower rates of migrant-engagement that have been demonstrated in study-based CVH testing interventions in GP practices in London [Hargreaves S 2014].

These variations are poorly understood, and heterogeneous, and may be changing over time. Indeed, recent analysis by PHE suggest that HCV testing has increased in the South Asian population by around 27%, and by 52% in the Eastern European population groups between 2012 to 2016 [PHE 2018]. However, there is likely to be variation based not only on the testing infrastructure and motivation, but also based on the migrant group, with members of the Pakistani community well represented in testing initiatives [PHE 2018, Flanagan S 2019], perhaps based on familiarity and peer-support of testing initiatives. And it is likely that more isolated and vulnerable communities, including the recently arrived Nepali community may demonstrate lower levels of agency to openly engage with these initiatives without support, and will therefore be strongly influenced by the support structure in place to offer testing engagement in local primary care services.

Prior qualitative studies in primary care have demonstrated gaps in the knowledge and confidence of HBV and HCV management in primary care. In the study by Guirgis et al, GPs identified difficulties with interpreting serology results for HBV and HCV, as well as gaps in the knowledge regarding long term

risks (including HCC) in CVH, and the effective management strategies for infection. One of the major barriers in migrant testing identified during this study was language, as well as perceived stigma, with the addition of a specific nurse advocate seen as positive intervention that may help facilitate testing delivery [Guirgis M 2012]. Primary care physicians have also demonstrated discomfort in approaching individuals for testing where risk activities need to be discussed, with concerns raised about discomfort in both the practitioner and patient in this process, and the same US study by Jewett et al. reports the perception from specialists that CVH testing lies at a lower priority than other conventional testing activity for cholesterol and similar established non-communicable diseases [Jewett A 2015].

Awareness and practice of CVH testing policy has been reported in an international and national context, including studies into the uptake of previous HCV testing policy in the UK. Studies in Australia among GPs and primary care nurses (n=20) identified low levels of awareness regarding national hepatitis B testing policy, and variation in confidence and patient communication that seems strongly influenced by the practitioners' experiences and patient demographics served [Richmond J 2017]. In the US, similar deficits have also been noted in previous surveys of primary care physicians (PCPs) towards national society guidelines [Kallman JB 2008].

Community based testing for viral hepatitis (HBV and HCV) is advocated in national and international guidance, with testing access via primary care a key facet in this approach [NICE 2012]. However, previous qualitative studies following the national HCV Action Plan in 2004 had shown poor understanding and awareness of testing guidance in primary care, as well as a poor uptake of HCV testing despite widespread dissemination by the Department of Health [D'Souza RF 2004]. Recent studies continue to show that most at-risk patients are untested in GP practices [Datta S 2014], suggesting a continued lack of engagement in HBV and HCV testing practice in primary care.

Little is known about the current awareness, understanding and practice of viral hepatitis testing for migrant communities in GP practices, with no qualitative studies undertaken in primary care since the introduction of NICE testing guidance; arguably the most powerful stakeholder in community based testing for viral hepatitis nationally. Our earlier focus group work with members of the local Nepali community has also shown a clear enthusiasm to engage with primary care physicians, with further need therefore to explore how testing is understood in this setting, with the aims to explore the potential barriers and facilitators towards testing in primary care, and to identify potential leverage points for action to improve community testing access and engagement.

Understanding the potential barriers and facilitators to overcome this gap involves an exploration of the current practice, awareness and perception in relation to this policy in day to day practice, which forms the basis of the current qualitative study.

Research objectives:

The aim of the current study is then to develop a qualitative strategy to identify these factors in primary care, with the following research objectives to address:

- To identify current CVH testing practice in primary care
- To explore the awareness and knowledge of CVH testing policy and policy objectives
- To identify the experiences and perception of viral hepatitis testing in primary care
- To explore the perception of CVH testing in migrant communities
- To explore potential barriers and facilitators to testing

Reflexivity:

In approaching this study, I was aware of my external role as a researcher in designing and conducting my focus group study, but also my internal role as a clinical doctor. My clinical role gives me both an insider status in view of my shared profession, and the patient care and interaction that I commonly have, but also as an outsider to primary care, representing a hospital specialist, and one who may be seen as trying to identify shortcomings in knowledge and awareness among practitioners not working as specialists in this area.

Ethics application was sought in part to re-assure participants of the confidential and professional research nature of the study. The focus group guide was designed to be focused and impartial, and to avoid deliberate questions that may be viewed as trying to “catch” individuals out.

During my moderator role, I was conscious that I would be seen as both research moderator, as well as hospital specialist in liver diseases. This relationship is likely to have influenced interactions, although participants appeared to respond well, and openly, and may well have led to increased interaction and discussion with GPs, who may have seen me as a colleague, and as an educational benefit.

Participants were also aware that there would be an educational sessions delivered at the end of the focus group, which may have changed interactions, although one would hope this would have further supported individuals to express their viewpoints.

Focus Group in Primary Care: Method

To study these issues, I developed and conducted Focus Group sessions with GPs local to, and serving the Nepali community.

The basic characteristics of focus groups centre on 6 key aspects: (1) the people, (2) assembled and interacting as a group, (3) all possessing certain characteristics, which (4) provide data (5) of a

qualitative nature (6) in a focused discussion [Kruger R 1994]. Utilising a focus group approach I will be able to draw together a group of GPs to explore my research objectives in depth relating to viral hepatitis testing in real life practice. Drawing together several GPs, I hope to utilise the social dynamic of the group to explore perceptions and practice in the group, and to probe further into this through group interactions. Limitations of focus groups include the generalisability of my findings, which although I hope these will be in-depth, may be most representative of the local population and similar GP practice settings across the country, but will be representative of the issues facing the local Nepali community.

Ethics approval was obtained through application to the University of Surrey (the study sponsor), with no formal Health Research Authority (HRA) ethics approval required after (formal) enquiry given my clinical NHS role and staff to staff interaction [[HRA 2013]. Ethics approval was still sought through formal channels at the University of Surrey to provide formal reassurance to our study participants of the rigour of our research process, as well as with the aims of future publications.

Practices around Aldershot, in Hampshire and Surrey, were recruited in a purposive manner through mailed invites to practice managers and lead GPs, as well as promotional presentations delivered to local CCGs, and adverts placed through CCG newsletter publications on a regional level.

Three practices were eventually recruited in Aldershot, with the Focus Group delivered during one of the regular education programme sessions arranged for these CCG linked practices. An educational talk on viral hepatitis, and an update on national and international testing guidance and new treatment paradigms was presented to the same group after the FG session.

The three GP practices chosen served the Aldershot area and the military barracks, and linked through a hub in the large multi-purpose Aldershot for Health complex. This served many of the known Nepali population clusters in and around Aldershot, and was also one the main GP hubs for many of the participants who took part in our community testing study in central Aldershot.

GP Participants knew each other from a work context at individual practices, or at the very least would have met and interacted at similar educational forum that were organised monthly. Trainee GPs would also have the likely added dynamic of being under the direction and assessment of one of the senior GPs on a day to day basis, although this relationship was not questioned or explored before or during the session. Identifying GPs who had not met or interacted on a regular basis was not deemed feasible, and not thought necessary to the overall aims to identify our research objectives.

A focus group question guide was developed within the study group (researcher and study supervisor) with the aims to understand the awareness, beliefs and practices relating to HBV and HCV testing, as well as potential barriers and facilitators to testing, with close liaison to NICE testing guidance aims

(Figure 25). I acted as the sole moderator during the focus group session, utilising the focus group guide to structure and prompt discussions within the group.

Questions:

1. How prevalent / relevant do you think viral hepatitis is in your practice population, and practice?
 - a. Something you think about/offer patients regularly?
2. Which groups / individuals do you offer viral hepatitis testing at present?
 - a. Which groups/individuals do you think are at-risk?
3. Community testing often defined as Case-finding – have you heard of this policy?
4. Do you / or any of your practices have such a policy of identifying and offering testing to at-risk groups?
5. Are you aware of/do you use any guidelines on viral hepatitis testing?
 - a. NICE/RCGP etc
6. How do you feel about offering viral hepatitis testing to asymptomatic individuals?
 - a. What have your experiences been of offering testing ?
7. How do you/would you approach the different at-risk groups?
 - a. Do you/would you approach them in the same way – migrant groups/sexual risks/IVDU?
8. Would you adopt case-finding practice into your surgery? How do you feel about case-finding as a concept in primary care?
 - a. How would you approach this?
 - i. Systematic / Opportunistic / New-patient testing?
 - b. How can primary care testing be improved
 - c. DoH Local/CCG level, Practice / Patient level
9. Does anyone have any other comments/issues they'd like to raise

Table 15: Focus group guide in primary care, and prompts for the moderator

Formal written consent was obtained from participants, with written information sheets circulated to participants before intervention. All sessions were audio-recorded with written consent.

The focus group was conducted over an afternoon session lasting 45 minutes in August 2014, with an information sheet that was disseminated to the session coordinator from the 3 practices prior to the session. The session was held at the Aldershot Centre for Health primary care seminar room, which is a designated space developed for meetings, and education sessions for primary care staff. The space was well separated from patient treatment/waiting areas, and was closed off from any other staff or office space environments.

Focus Group data was analysed using the Thematic Analysis methods identified earlier by Braun and Clarke, working within a realist evaluation (RE) theoretical framework to explore the expressed meanings of participants with close association to societal and contextual factors [Braun V et al. 2006]. Analysis was conducted according to our research objectives, utilising the earlier framework to define these objectives within a Health, Political and Social context.

Findings:

A total of 9 GPs took part in the Focus Group study with written consent obtained from all participants. 3 of these GPs were military doctors, with the remaining 6 who were civilian GPs; 3 of the participants were GP registrars.

Initial coding identified themes ordered around our question guide exploring: knowledge and awareness, perceptions and priorities, as well as potential barriers to testing (fig 26). Analysing focus group data through a thematic analysis framework identified four overarching themes, which are discussed in detail in the following sections: “Fear of Racism”, “Testing Causes Harm”, “We are Overwhelmed”, and “A Low Priority”.

A network map of these overarching themes is presented in fig 27, with a summary that is presented

A Fear of racism:

An overarching theme that explores the perception that testing in migrant groups may be viewed as prejudiced. The fear of being seen to act in a suggested racial manner is expressed as a potential barrier, and suggested risk to practitioners.

Testing causes harm:

An overarching theme that explores the strongly expressed harms that can be seen to both patients and their families through testing, and the analogous associations expressed towards case-finding and screening.

We are overwhelmed:

An overarching theme that explores the resource pressures that GPs see themselves under, and the potential difficulties that they associate with the addition of a viral hepatitis testing programme.

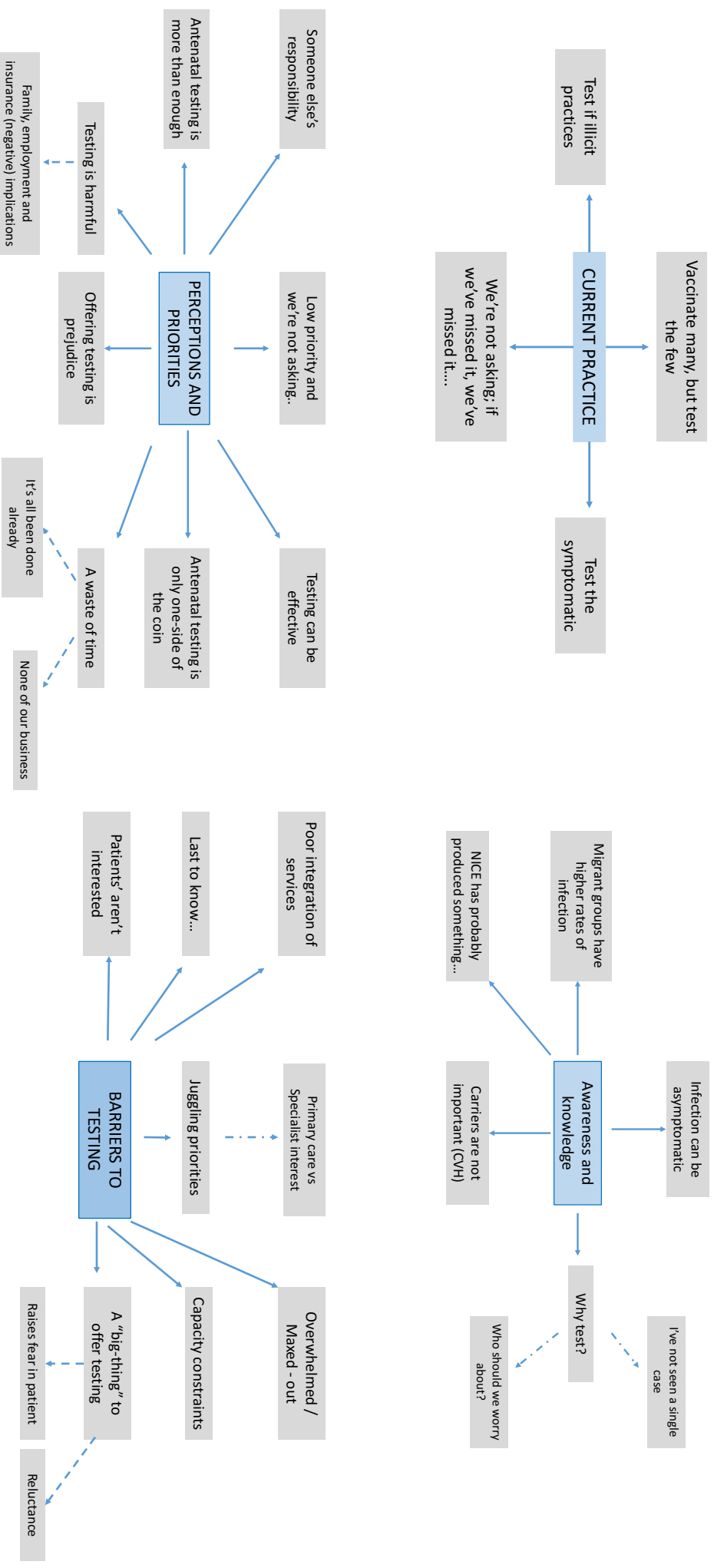
A low priority:

An overarching theme that explores the lack of perceived responsibility for viral hepatitis testing in primary care, and the lack of current awareness and expressed priority for testing in current and future practice, as well as a low suggested priority for those established with chronic disease in the community.

in table 15.

Figure 25: a network map of the principal candidate themes which produced the four higher order overarching themes in final thematic analysis. Dashed line represents linked association between the candidate theme “juggling priorities” between the two overarching themes “ We are overwhelmed” and “A low priority”

Figure 25: Initial themes identified in focus group analysis in Primary Care



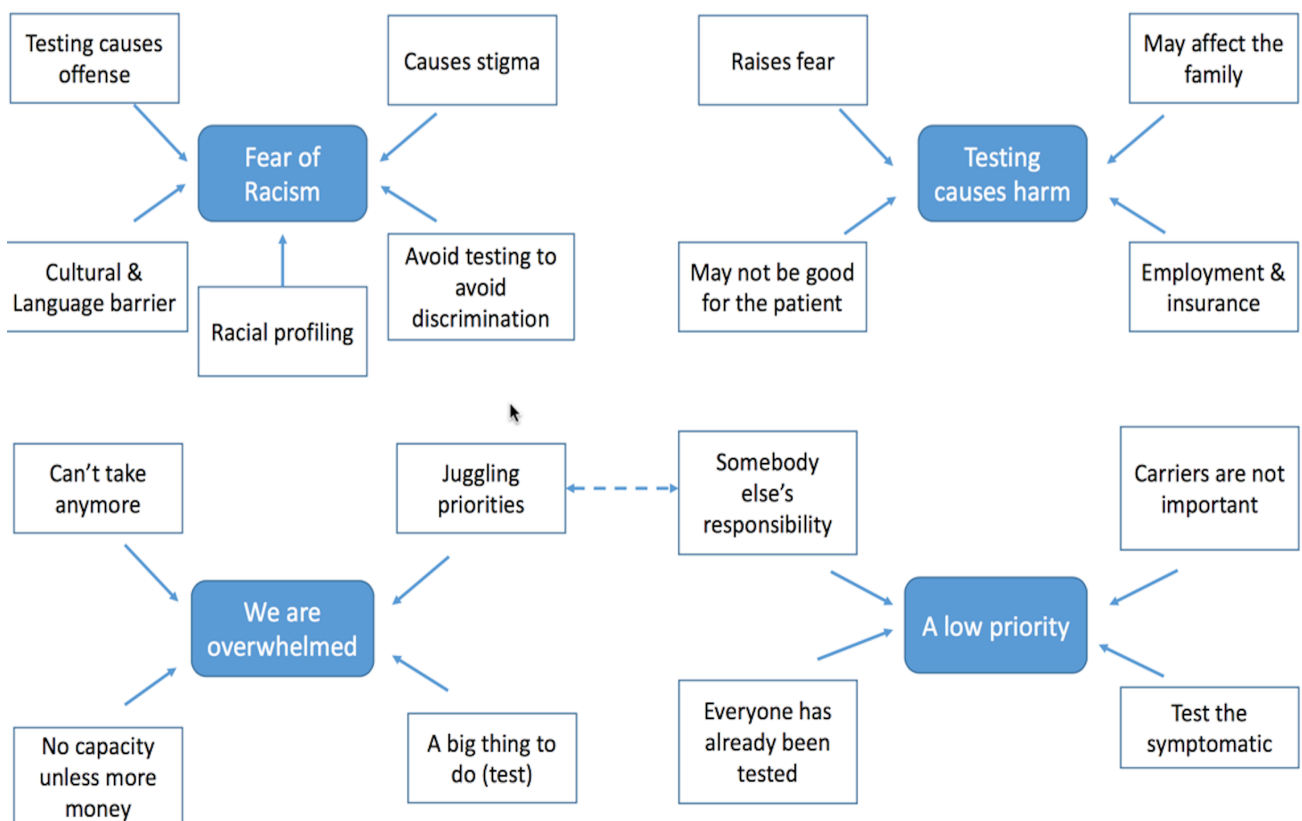


Figure 26 – a network map of the principal candidate themes which produced the four higher order overarching themes in final thematic analysis. Dashed line represents linked association between the candidate theme “juggling priorities” between the two overarching themes “We are overwhelmed” and “A low priority”

Overarching themes identified in focus group analysis

Fear of Racism:

This overarching theme explores participants’ expressions that approaching migrant groups for HBV and HCV testing is fraught with the risks of appearing or acting in a racist manner.

“There has been a suggestion within the military services that we actually test everybody, but there’s been a lot of resistance to that, as it was perceived as racially motivated, because obviously we have a lot of foreign and commonwealth soldiers, and therefore they are going to be primarily that we would go on to expect to have infection, although that’s not completely true…… (Participant 4)”

Testing in military personnel has clear implications for work and deployment, and is not captured in NICE community viral hepatitis testing guidance [NICE 2012]. However, it is interesting to note firstly the awareness that exists regarding infection risks in different migrant groups, and also the wider perception within discussions that such Case-finding strategies could be viewed as “racially-motivated”, thereby avoiding testing in these groups, and perceived acts of discrimination.

Other GP participants expand upon this to discuss perceived difficulties based upon cultural and language difficulties, as well as perceptual fears linked to testing offers:

“there is kind of a bit of a barrier (nods of agreement in room)”; *“especially if you’ve got a population with a cultural or language barrier already, they may not take it well for something unrelated, and it can cause offense in some people as well (Participant 7)”*

Here, participants’ express concerns that testing can cause offense to patients based upon cultural perceptions of health, as well as miscommunication due to potential language barriers. The implication here, is that testing is seen as stigmatising to patients, and crucially that it may be seen as racially prejudice to discuss testing with migrant groups.

This viewpoint is mentioned by several participants of different backgrounds in the group, with concerns about how testing will be interpreted by those in migrant communities:

“And also, is it not going to be judged again....., as being prejudiced against one racial group, rather than everyone?” (Participant 6)

Against this widely held sentiment in the group, only one participant offers a counter narrative, with analogy drawn towards testing offers in another population group in primary care, and the potential benefits in identifying disease if present:

“Well it’s like Chlamydia testing, it can be thought of as prejudice, but we still do it. Naturally Once you’ve identified a population group, you know, its nor, I don’t think it’s like.... [...] You’re giving them the option, and I think it’s better to pick it up and treat.... (Participant 3)”

However, this sentiment is not echoed in the group, with a rapid and concise rebuttal to the participant by others in the group:

“Yes, but that’s just one example.... (Participant 8); But screening has harms as well as benefits (Participant 5)”

Here, the participant echoes the earlier expression that testing offers in migrant populations raises its own perceptual risks towards prejudice, and that such testing cannot be seen as analogous to testing offers in other at-risk groups. Wider support for the potential benefits of testing, and disease awareness is not expressed by other GPs in the group; indeed, the second participants expression

relating to the potential harms of testing is a direct response to this, and forms a strong overarching theme (Testing causes harm) in the focus group analysis.

Testing causes harm:

The potential harms of testing programmes are described by many participants in the group, with the suggestion of additional responsibilities that GPs have to identify, and perhaps even protect patients from these risks:

“[...] but screening has harms as well as benefit [...] if we talk about screening, we’ve got to think about the harms, and like you say discussing what the implications are for family members, what the implications are for future insurance..... (Participant 5)’

Case-finding is described here as screening, and GPs perceptions regarding testing may therefore be influenced by perceptions towards large scale testing programmes in other disease states such as cancer care, and the potential difficulties with false positive results [Loberg M 2015]. But despite this, there are specific concerns regarding the harms that testing can cause to the individual as well as the wider family.

The potential negative implications of testing are discussed by several participants at various points and contexts during focus group discussions. Whether these harms are specific to just positive test results are not made explicit, but regardless these potential harms are strongly expressed by several participants in the group:

“[...] then you’ve got to talk to them about the implications of having this test, and for your nearest and dearest and things like that, and it could have an effect on their employment and things like that, and their ability to get insurance.....(Participant 3)”

Significant personal and even familial harms are described here, with a responsibility that the practitioner also has to inform their patients prior to testing offers. The reasons why testing would adversely affect the family is not expanded upon here; whether this is due to stigmatisation, or some other harm to internal or external relationships. There is also no recognition here of the very important goals to identifying disease in any at risk relatives, and preventing onward transmission. Similarly, the impact on employment and insurance is not made explicit, and certainly healthcare is relatively unique in the close involvement of occupational health, and importantly the fact that there are no blanket restrictions on those with BBVs working in healthcare [DoH 2000, HPS 2008]. On insurance, the participants’ expression suggests a detriment or exclusion to being granted insurance because of having viral hepatitis, and perhaps just the activity of testing itself. However, this is contrary

to guidelines through which insurance companies practice, with no requirements to question clients regarding previous testing activity (presuming negative) outside of certain large value policies [ABI 2010].

Overall, the participants' expression describes many risks with testing across health, social and economic aspects, with the suggested concern that GPs put across regarding the potential fear that patients may be exposed to in taking part in testing.

We are overwhelmed

The pressures that GPs face to meet current demand is clearly evident in focus group discussions, and is identified as one of the overarching themes in focus group analysis.

Participants describe the difficulties that they face in meeting day to day needs, as well as the demands and challenges that GPs see with the thought of any additional procedures, including viral hepatitis testing:

"[.] Well we really are overwhelmed with workload, and currently we haven't got capacity unless there is some money involved. [...] Just from our practice, the secretaries are overwhelmed, so right now, unless there's some, something... I think we're all..... (Participant 9)"; "maxed out that's the word (Participant 5)".

The participant identifies here the significant pressures that GPs are under to meet existing demand, and the need for more resources, with the specific mention of financial input to even consider taking on extra commitments. There is even the suggestion of resignation or perhaps exhaustion in how to label and address these pressures in primary care.

As well as these pressures, GPs express concern that viral hepatitis testing presents a significant additional burden to add on to day to day practice:

"[...] it's quite a difficult one to just go... well while you're here whoops, let's talk about hepatitis B and C testing, but also it is not a straight-forward thing to describe to somebody, and they've probably never heard of it, then you've got to talk them about the implications of having this test [...] and so it's not a small thing, and you're going to say, well why don't you have a test whilst you're here (Participant 3)"

Testing here is described as a significant and likely uncomfortable commitment, and “no small thing” for GPs to take on. It also suggests a barrier that exists as a result of the significant information that has to be shared with patients before testing can be adopted.

The potential challenges to GPs if a successful testing scheme was established is further expanded on by others in the group:

“[...] The only problem is that the onus is on us as the practitioner, when you’re promoting screening to chase up results, and so it is going to be a whole new burden. If you can educate people to come to you, then the onus is on them to come forward and get the results. (Participant 4)”

Here, the participant identifies the potential additional workload that testing would create, but also potential strategies to facilitate testing that may be seen through patient education, and is the first (and only) among GP participants to suggest a role for patient ownership of testing through education.

A Low Priority

In addition to the challenges that a viral hepatitis testing programme would pose to primary care, practitioners identify current testing practice, and responsibilities towards testing that feature low on most practitioners’ priorities, and with some expressing very strong views to counter the need for viral hepatitis testing in any form in primary care:

“I’d say that it is a complete waste of money, because it’s all being done anyway. And we screen all the antenatals anyway don’t we?... [Participant 2]”

The participant here expresses disdain at the prospect of ongoing or escalated viral hepatitis testing practice, that seems based on assumptions that testing practice is engrained elsewhere in the health service, including antenatal care, despite the absence of routine antenatal HCV testing nationally. On discussing the lack of HCV testing that currently exists in the antenatal system, the participant continues to express a negative view towards testing practice:

“no, we don’t do hep C. I get all the results from our practice, and they’re just tagged on to my inbox, and I’ve not seen a positive one, and they check it twice, why? You know, It’s just one of those stupid things isn’t it?...[Participant 2]”

There is little encouragement here regarding the participant’s views towards testing, and this seems closely linked to a lack of first-hand experience with positive cases, as well as perhaps the work load involved with looking through these results. And even after another colleague discusses a positive co-infected maternal case that they have encountered, the expressed viewpoint does not change:

“I appreciate the HIV patient, but I’ve not seen it recently in the routine screens [Participant 2].”

The responsibility for testing, and the role of primary care in viral hepatitis testing is also queried by several participants:

“one thing that’s quite tricky, there’s a lack of communication between the sexual health clinic and us, because they’ve got all this confidential information, so we never quite know what they have tested [...].”

“[...] there are plenty of people who have been screened, and we don’t know about it as their GP, and they will get tested by blood-spot testing in drug-and-alcohol clinic, and we don’t get told those results either [Participant 3]”

Participants express frustration here that testing often occurs in other community settings, where information transfer may be limited, and responsibilities for testing that some may see as residing in these community centres as a result.

Participants seem to express little certainty regarding testing indications, and in relation to national guidance, with a low priority that is associated overall towards current testing practice:

“NICE has probably done something...; but I haven’t read it.. (Laughter) [Participant 3]”

“[...] and we don’t always know who the at-risk groups are, and we’re not constantly asking the question. We’re all so busy, that to actually go through a whole load of screening questionnaires.... if we’ve missed it on the new-patient check, we’ve probably missed it... [Participant 8]”

None of the participants seem aware of NICE testing guidance, and although there is acceptance that national guidance may indeed exist, there is the implication that the subject and perhaps principal of multiple guideline documents are a low priority, or do not fit into their current working patterns or context; akin to the principals of the “second translation gap” identified during studies of evidence based research, and guideline adoption into clinical practice [Lau R 2016]. A lack of awareness of at-risk groups and testing indications seems to combine with the perception that case-finding assessment is challenging, thereby confounding the likelihood that GPs will engage in testing practice. Although the latter participant expresses the suggestion of testing on new-patient registration, it should be noted that none of the GPs expressed any such practice that currently exists after direct question probes during focus group discussions.

Further expression of the low priority in which viral hepatitis testing is seen is provided again by Participant 2:

“In over 25 years as a GP I have never seen a case of hepatitis B [Participant 2]”

This assertion is queried by others in the group, with the subsequent reply that raises further concerns regarding disease awareness and understanding:

“No it’s never come way at all, no never! Hepatitis C carriers and things that got picked up by, but not a hep B case.... And I worked for a hepatologist, and I would be thinking about that... [Participant 2]”

“Do you mean acute as opposed to carriers? [Participant 6]”

“I mean acute.... Yeah [Participant 2]”

The interaction here highlights the low priority through which viral hepatitis is currently seen, as well as being suggestive of misconceptions regarding disease understanding and management. It is unclear if the participant is referring to acute or chronic viral hepatitis, and most likely this relates to uncertainty between the two states. Regardless, it wrongly implies that chronic HCV carriage is a benign state, rather than one that necessitates referral and treatment. Whilst it may be that the practitioner has not encountered a chronic HBV case, it does raise the same important concerns around the definitions and understanding of acute and chronic HBV related liver disease, and overall raises concerns in how new migrant communities would be assessed and treated with these preconceptions, given the likely variance in disease prevalence to the background UK population.

The difficulties that GPs see though towards viral hepatitis testing, and in prioritising testing practice in their current constraints is well illustrated by Participant 5:

“Every particular specialist will think that they’re, umm area is really really important, and should be a priority of us. And so we have to juggle all of those.... [Participant 5]”

This extract highlights the issues that GPs see in trying to “juggle” the demands of specialist, hospital based teams in achieving goals that are presented as external, and likely outside the current responsibility and ownership of primary care physicians.

Key findings:

GPs express awareness of CVH as a risk for liver disease in their patient cohort, and whilst there is knowledge of treatments for CVH, the overwhelming perception portrayed is that CVH testing is a low priority area, and one that may cause offense, and even harm.

Knowledge of CVH with regard to its effects and complications is not discussed explicitly, but there is the suggestion of misunderstandings in the relationship between acute and chronic infection, and the need for monitoring, referral and treatment. Treatment options are also poorly understood, with no reference to newer agents.

Knowledge regarding case finding and national guidance is poor, and whilst some in the group express awareness towards testing in migrant groups, the overwhelming perception is that this will lead to offense and potential harm. There is also misunderstanding in the personal and familial impact that CVH testing can have, with incorrect beliefs towards the work and insurance implications of CVH testing, which could further impact case-finding activity in primary care.

Chapter 6

*Developing CVH case-finding strategies in the
Nepali community*

Chapter 6: Developing CVH case-finding strategies in the Nepali community

SUMMARY:

At the heart of our study are the potential risks of CVH faced by the newly arrived UK Nepali community, with qualitative studies that have demonstrated an interest to engage with health professionals, and primary care studies that have identified testing practice as a low priority in migrant communities.

Developing testing interventions to successfully reach out to this population is therefore crucial in assessing this risk, with difficulties that exist in comparison to testing studies in other, more established migrant communities, where religious homogeneity, or established community meetings facilitate study promotion and engagement.

Context

Nepal sits between India and China, countries with higher established CVH risks, but with the burden of HBV and HCV that are not well understood in the unique Nepali population extraction that now resides in the UK.

To understand this risk requires a community-based approach to explore disease prevalence, with a testing strategy that needs to be developed to identify and engage with members of this new and heterogeneous community.

Utilising the findings from our qualitative studies in members of Nepali community, as well as local primary care physicians, there is evidence of interest in engagement for CVH, with first-hand experience of jaundice that is mentioned by many participants, further emphasising the need for study. Our qualitative studies in primary care also suggest that current testing practice in primary care is likely to be at a low level, with a need therefore to develop strategies to engage with members of the local Nepali population in a community setting to assess disease risks.

Community testing strategies for CVH and BBVs have been successfully delivered in several migrant communities in the UK, often targeting common places of worship, or pre-existing community groups, but with limited studies, and unique demands that exist in identifying recruitment and engagement strategies in new migrant communities, such as the Nepali population.

Community testing strategies: Literature review

Recognising the higher burden of CVH among migrant communities, there has been several large scale studies that have looked at engaging with communities for HBV and/or HCV testing, with engagement rates and disease prevalence rates that have differed between study groups, and the populations studied.

The term “Community” can be used in different contexts, whether as a descriptive term to define large numbers of a group and its’ population; but also may be considered as a more developed unit where a shared identity or belonging can be utilised to support and further develop a policy objective in the community as a whole [Whitehead T 2002]. Similarly, community based interventions (CBI), which is the umbrella term that considers testing interventions, can also be defined in several constructs, based on the degree of involvement, and relationship between the specialist, or policy group, and the “community” as a whole, with the ideal CBI being a “true partnership between technical experts and the communities they serve” [Robotin M 2014]. This model involves the expert group providing conceptual rigour, comprehensive study design and thorough implementation, with community involvement to support program incorporation into a sociocultural context [Robotin M 2014, Whitehead T 2002]. As such, the development of community support is therefore crucial from this analysis in the design and development of community based interventions.

Most published studies focus on testing strategies in established migrant communities, typically utilising lay community or religious leaders to facilitate testing recruitment and engagement. There is heterogeneity between studies, and the success of testing uptake is often not apparent, with difficulties in knowing the pool of eligible/invited individuals for testing (outside of mailed invite studies). Nevertheless, testing uptake can be inferred by the overall study size, and number of participants and recruiting events required to achieve this target.

Multiple strategies have been trialled for patient recruitment, as well as testing engagement, with varied successes. Mailed testing invitations have been successfully employed in studies in the Netherlands, utilising migrant registration data held by the municipality to generate testing invitation. In the study by Veldhuijzen et al. they issued invites (plus a reminder letter) to 1787 Dutch-Turkish individuals, achieving a testing uptake of 16% (288/1787), with the addition of regional newspaper advert and website promotion improving this uptake to 30% [Veldhuijzen 2009]. This uptake is higher than that previous achieved in the Netherlands using religious and community leaders alone in the same migrant population (around 10%) [Richter 2014], but does rely upon the coordinated involvement of regional government in recording and writing to migrant individuals for testing. It is perhaps also prudent to note that the same population expressed high levels of dissatisfaction with the Dutch healthcare system, and whilst this is not unique among migrant groups in Western healthcare settings, there is no exploration whether the involvement of local government in this process (through mailed invites) plays a part in this dissatisfaction.

In the review by Robotin et al. several partnership approaches are suggested in developing and providing community based interventions, with an outreach and partnership model (OPM) more

successful than other approaches, including integrated community clinic testing in primary care; and partnership and contract models, utilising a contracted company to facilitate testing activity with the community group. In the OPM approach, community based interventions continue under the study group, but with close involvement of community advocates in organising and facilitating the study [Robotin M 2014].

In the UK, community-partnership approaches have been tested in the South Asian community, utilising religious and community settings in Mosques, Temples and established community venues. Such approaches and settings seem to be popular, with close to 4600 individuals tested in (primarily) religious settings across the UK by Uddin et al. (around 29 individuals per session). The direct support of religious leaders, and the delivery of testing at the place of worship (through finger-prick blood tests, or mouth swabs) do seem to be important, with the same group showing no uptake in blood test requests when 5000 invites were distributed to a Mosque without local testing [Uddin G 2010, Lewis H 2011]. Similar methods, utilising primarily religious settings have proved successful in studies in the Egyptian Coptic community, and in the Korean Christian community in the US, achieving a high number of HBV and HCV tests in these populations, with around a 100 individuals tested per session in the US based Korean Church study [Zuure 2013, Navarro 2014]. Similar studies in the Chinese community in the UK have used established community venues, Churches and local Wholesalers to advertise testing, with testing uptake in around 230 individuals (around 15 individuals per session) [Vedio AB 2013].

Behavioural modification has been attempted by researchers in the Netherlands, providing behavioural and cultural prompts to link HBV and HCV tests to religious (Islam) and cultural beliefs of healthcare, and wellness. Such methods have not shown a clear benefit in testing uptake, but perceptions towards health and testing were higher in those individuals receiving behavioural interventions with the potential for these strategies to have benefit over the longer period in healthcare engagement in migrant communities [Van der Veen 2010].

As such community partnership models with support from religious and community leaders seem an effective route to approach migrant groups for testing, but with the limitation that these measures are largely restricted to those established migrant groups with existing community venues, or religious homogeneity.

The largest and well-funded community testing program is perhaps the “BfreeNYC” project undertaken between 2004 and 2008 in New York City, which tested 8,888 migrant individuals (principally of Chinese and Korean descent) for HBV. This was a large-scale coordinated testing

program “championed” by city councillors in a top-down approach, and funded to advertise testing on large scale in major media outlets. Large scale advertising on this scale was successful in achieving community awareness in around 10% of the migrant population. Stigmatisation was not reported from the wider community during this advertising process, and importantly members of the Asian community associated less stigma towards viral hepatitis as a direct result of the awareness-raising programme [Pollack 2011, Yoo GJ 2011].

Most community testing studies focus on testing in one community, with the Dutch study by Richter et al. one of the few to describe testing in multiple geographically-separate migrant communities in a single event. This study is also one of the few to focus on just first-generation migrants, although the duration of residency in the Netherlands is not apparent from the study. Individuals were again identified and directly invited by mail from the local municipality. Advertising was delivered in local media sources (newspapers, websites), with no mention of any undue stigmatisation in the wider community, and with an uptake of HBV and HCV testing in 959 out of 3226 individuals who attended a community talk delivered by hospital physicians. Individuals attended from Asia, Eastern Europe and the Middle East with marked cultural diversity, but with reasonable levels of engagement from all groups. Rates of infection differed between communities, but the high levels of uptake in first-generation migrants from different populations is encouraging [Richter 2014].

Linkage to care for positive cases/disease risks is poorly documented in most studies, with high rates of individuals lost to follow-up in most studies; and even in the most comprehensive testing intervention in the BFreeNYK study, around 57% of participants were kept in care services until the end of the 4 year study [Robotin M 2014].

In all voluntary community-based approaches, self-selection bias a common factor, and it has been suggested that rates of infection may indeed be higher in those individuals who do not take up such offers, due to co-morbid disease, or risk-activity that makes them paradoxically reluctant to attend [UddinG 2010]. Whilst primary care testing is an alternative that may reach out to these individuals [Rein 2011], recent studies in West London have shown poor attendance (10%) by members of migrant communities in specially prepared new-patient testing sessions, despite an estimated local migrant prevalence of over 40% [Hargreaves 2014], and our primary care focus group work has demonstrated a low priority, and current testing practice for migrant communities, including members of the newly arrived Nepali population.

Summary:

Overall, the evidence from these community endeavours show that successful CVH testing can be achieved in non-healthcare settings, with several testing strategies that have been employed. Media advertising has been used in the largest of testing studies in the BfreeNYC project [Pollack H 2011], as well as the study by Richter et al. with no significant reported stigma raised as a result of this advertising in either study, although arguably the current climate and sensitivities towards migration is likely to be more acute than the studies from 2008 and 2011 [Pollack H 2011, Richter C 2014]. Most projects though have focused on utilising existing religious and cultural settings to reach out to a migrant community with religious or other community leaders acting as testing advocates to promote health and testing, with this being the predominant approach utilised in the UK.

Rates of CVH infection identified in studies also varies, with heterogeneity that is likely to exist within and between individuals from the same region, as well as a lower rate of infection that may be suggested in second generation migrants [Uddin G 2010], but with many uncertainties that still exist, and a higher prevalence of CVH that is suggested in most studies cumulatively.

The optimal strategy to engage with, and test members of the newly arrived Nepali community is therefore unclear, with most study data available for established communities with an existing religious, or community link to disseminate and encourage testing to a population that shares a common focus and/or attendance through this religious/cultural activity. It is evident though, that community based support and advocacy is crucial to testing success, with the need therefore to explore and develop community links within the Nepali population in building testing sessions.

Research Objectives:

The hypothesis of our testing study was that rates of CVH would be higher in the Nepali population, with higher rates of infection that may be seen in newly arrived, first-generation migrants, as opposed to those Nepali born in the UK.

The primary objective of our study was to develop a community based testing intervention to explore HBV and HCV prevalence in the local Nepali population:

- To develop and prove a successful health-engagement strategy with large numbers of the local community
- To identify CVH (HBV and HCV) prevalence in the Nepali community

Our secondary objectives were to explore potential risk-factors that may be associated with past or current disease, as well as factors that influence the success of engagement strategies, onward linkage strategies to secondary care, as well as potential contact tracing implications of positive cases.

- To explore potential CVH risk factors associated with past / current infection including:
 - demographic factors, geographic variation, educational status, alcohol, blood borne exposure risks
- To explore potential barriers and facilitators to community testing engagement
- Explore linkage to care in secondary health services
- Explore potential contact tracing implications of positive cases

Reflexivity:

As a first-generation migrant, although at a childhood age, I am conscious that I am likely to treat this group differently, and feel comfortable interacting with migrant communities in general. My experiences in secondary care working with members of the community in an outpatient setting has shown these individuals to be engaged, and nearly always accompanied by a friend or member of the family from the Nepali community.

Language is likely to be a significant barrier to communication, and my interactions with members of the local community has demonstrated this in clinical practice, with the frequent need for a translator in clinic visits.

Testing a large number of Nepali in the community is likely to present a challenge, with a significant heterogeneity in religion and caste, and the resultant lack of a common forum to promote or engage with members of the community.

Methods:

Ethics:

Formal ethics approval was obtained through the National Research Ethics Service (NRES) and Health Research Authority (HRA) (Brighton and Sussex NRES committee; ref: 12/LO/1530; IRAS 114296/363341/14/402) for activities relating to focus group discussions in the Nepali community, as well the testing activity of the current study [Appendix x]. The study sponsor was Frimley Park Hospital, with original ethics application submitted by one of the research supervisors, Aftab Ala (AA).

Study Design:

Community Leaders: Given the uncertainties that exist in how to approach and test this new community, as well as potential sensitivities that may arise, we first established a multidisciplinary research team with close input from Nepali community leaders and community stakeholder groups. Support was gained from local public health commissioners in Hampshire, and Surrey and Sussex (PHE, formally known as the Health Protection Unit), community liaison workers at Frimley Park Hospital, local council representatives, as well as the British Liver Trust patient charity. Study design was influenced by the findings of our qualitative work with the local Nepali community, with the study design reviewed by national Hepatology (Clinician) leads prior to testing activity.

A steering group was formed between the research team and Nepali community leaders to coordinate and deliver testing activity, including the initial focus group activities of this study. This group acted to inform and direct testing activity, and also to act as peer-support for testing in the community. The core researcher team was made up of myself (SM), Dr Jane Hendy (JH), Professor Aftab Ala (AA) and Mihalea Petrova (MP).

Given the religious heterogeneity of the Nepali community, its recent arrival and expansion, as well as its potential vulnerabilities from a social determinants model, we developed our team of Nepali community leaders and volunteers very much from its' infancy, with little in the way of existing healthcare engagement strategies in place.

Initial, and key contributors to our research group included Ramji Tiwari, working with Rushmoor Healthy Living, and input from the Gurkha Welfare Trust. Nursing staff at Frimley Park Hospital also

contributed as volunteers, and to direct us towards other community volunteers. Ramji Tiwari was identified as having had public health experience in Nepal, and was afforded honorary researcher status to act as our principal spokesperson in community liaison in the initial stages of the study, and was provided financial support for his work in the study. Ex-Gurkha veterans were quickly identified as community leaders to engage and direct activity, with a strong community standing given in view of their military rank, and the predominant Gurkha ranks of the newly arrived community.

I became aware of existing Nepali Diabetes support groups, and a Macmillan cancer charity support group in community venues, and met with these groups to discuss testing objectives and strategies, and to recruit Nepali volunteers to act as eventual peer-advocates in our testing work.

Council leaders signposted me to projects running through local churches in the Farnborough area, and I presented our testing work at several large meetings, with the close support and peer-advocacy of ex-Gurkha veterans who chaired these sessions. The majority of Nepali community leaders were identified from the Farnborough and Aldershot areas, but with smaller community groups subsequently identified through my travels, with involvement and recruitment at these areas in addition, growing and recruiting our network of community leaders.

Our final network of Nepali community leaders was therefore identified through an iterative, step-wise approach, relying on word or mouth, and signposting to separate community groups of different sizing and populations. Multiple face to face presentations were then made to promote and recruit to our testing endeavours. Gurkha veterans were often (but not always) the chairs of these groups, with their support vital and instructive in promoting testing uptake.

Study location:

In consultation with our research steering group, the majority of the local Nepali population are thought to live in clusters, with suggested concentrations in Aldershot, Camberley and Farnborough in the areas around Frimley Park.

Study locations were drafted after consultation with local community leaders group, and input from our stakeholders. Hospital and healthcare facilities were considered in discussions, but discounted due to the “community-testing” aims of our study, travel requirements, as well as capacity issues that were thought to exist in accommodating testing sessions on-top of existing work commitments.

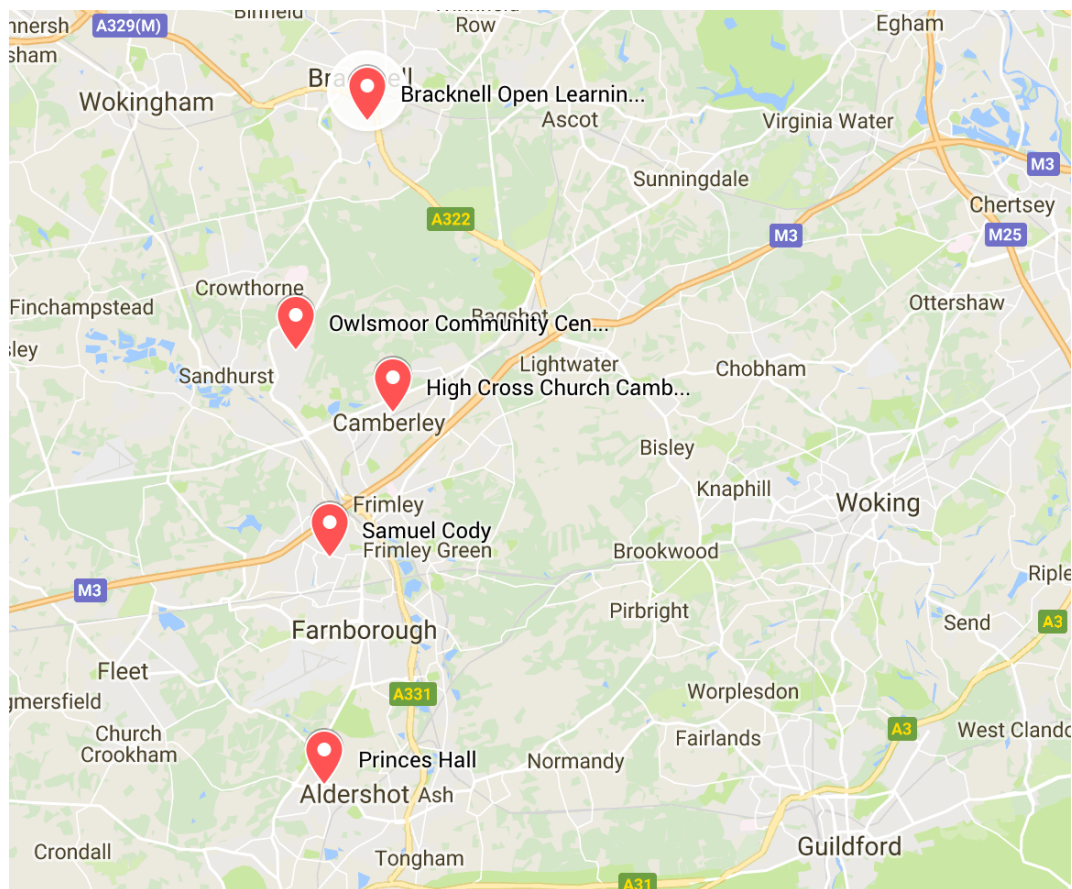
Testing locations were strongly influenced by new escalations in anti-Nepali sentiment reported to us by the research group, with Nepali leaders reporting intimidating leaflets, and concerns of violent

encounters with far-right groups, such as the English Defense League. Similar concerns were also echoed from other stakeholders in the research group, with the overwhelming aims therefore to deliver testing in settings close to Nepali population clusters, and in locations that would be regularly frequented by members of the local community, and unlikely to draw attention from the wider local community.

Locations were also suggested in Nepali work settings, and in college/educational settings to reach out to younger members of the community, but with concerns about stigma that may be raised in the employer/broader environment through this activity.

5 testing sites were eventually chosen, serving the areas of Aldershot (Princes Theatre), Farnborough (Samuel Cody School), Camberley (High Cross Church), Bracknell (Open Learning Centre, Bracknell) and Sandhurst / Owlsmoor (Owlsmoor Community Centre). All sessions were held separate to other scheduled events at these centres (figure 28)

Figure 27: Location of 5 testing sites in Surrey and Hampshire:



Princes Hall Theatre, Aldershot:



A large, multi-purpose site, centrally situate in Aldershot, with surrounding green spaces, that are frequent spots for Nepali communities to meet



High Cross Church, Camberley



A central position in Camberley, holding local community events, and well known to members of the local community from other events.



Samuel Cody School, Farnborough



Well used hall spaces (outside term time/school working), well known through (previous) Nepali events held in these halls. Away from the more commercial Farnborough town centre, where large Nepali congregations may seem out of place.



Owlsmoor Community Centre, Sandhurst



Well positioned in Sandhurst, and known to the community through local social enterprise schemes running self-help groups to the Nepali community.



Bracknell Opening Learning (community centre)



Well known and attended, with English-language courses to the Nepali community.



Study recruitment:

Advertising / participant recruitment

Initial study protocol and ethics application had included the recruitment aims to advertise our testing study to adult (>18 years) members of the local community in appropriate sites frequented by members of the community, as well as Nepali TV and Radio. Other members of the study group had previously run a successful testing study in the Shah Jahan Mosque in Woking, with widespread reporting, including on the local BBC website [BBC 2011].

However, given the concerns of anti-Nepali sentiment at the time of our study, we did not engage with any formal advertising at the outset of our study, relying on word-of-mouth within the community, as well as formal (translated) presentations in other activity groups, and community events. As the study progressed, some leaflets were distributed in Nepalese only, with radio adverts placed at the final part of our study on the local (Nepali) Gurkha radio networks.

Study promotion was conducted through formal and informal presentations to existing Nepali community groups and gatherings, including the Nepali Diabetic group, the Nepali World Cup festival (with a formal festival stand), the Madat Samuha Nepali group (St Mark's Church), and Nepali adult education sessions run by community volunteers in the local area. Radio adverts were placed on the

2 main Gurkha radio networks, with written information and formal discussion of our study aims, with the presenter delivering a translated version of these aims.

Participant (study) numbers

Initial study design hypothesised that individuals at higher risks of CVH may have prevalence rates of >2%, compared to baseline CVH rates close to 0.5%. Given the uncertainties of CVH rates in the newly arrived community, and engagement rates towards testing, an initial recruitment target of 500 individuals was set, with an overall aim towards 1000 based on initial feasibility assessments.

Testing method:

Finger-prick Direct Blood Spot (DBS) testing was chosen to perform HBV and HCV testing, with the aim of providing practical and tolerable testing in non-healthcare settings. DBS testing kits were obtained from the Central Manchester University Hospitals virology laboratory, with samples returned and processed at the same unit (figure 28). Mobile sharps bins were taken to all sessions, as well as clinical waste bags, with this material appropriately managed on return to Frimley Park Hospital in keeping with standard procedures.



Figure 28:: Dry Blood Spot (DBS) paper testing kits, with representation of the 5 “boxes” blotted with blood from fingerpick assessment

DBS testing has been validated in health studies, and is recommended in national policy, particularly in scenarios where conventional phlebotomy may be challenging, with reported sensitivity and specificity rates for HBsAg, HBcAb and HCV Ab reported close to 100%, [Mohamed S 2013, Vedio A 2013, PHE 2014]. Genotyping and HCV RNA testing can also be performed on DBS kits, with high levels of concordance reported (100%) to conventional serology [Greenman J 2015]. Internal validation data from the providing Central Manchester laboratories is provided in figure 29.

DBS Test Performance

Test	Sensitivity %	Specificity %	Limit Of Detection (IU/ml)
Anti-HCV	100 (96.48-100)	100 (97.57-100)	
HCV RNA	100 (95.1-100)	100 (96.1-100)	373 IU/ml
HBsAg	100 (96.41-100)	100 (97.45-100)	
Anti-HBc	87* (79.21-92.73)	100 (97.1-100)	*100% in HBsAg +ve, 87% in HBsAg -ve

Figure 29: Internal DBS validation data on HBV and HCV testing from the Central Manchester laboratory

Testing activity:

A multidisciplinary team was used to organise and deliver testing at each event, made up of the researcher (clinician), as well as research nurses, student nurses, and members of the Research and Development team at Frimley Park Hospital, working with community leaders to inform, consent and test (trained nursing staff) participants.

All patients were given Patient Information Sheets (PiS) on arrival, with Nepali moderators at the doors of each testing site to assist participants. PiS's and consent forms were developed in Nepali and English detailing the study aims, as well as basic information on CVH, and the implications of positive diagnoses (Appendix). Participants were given unique identifier numbers on entry, which was linked to their samples, and in follow-up to provide results.

Initial testing aims were to separate men and women into different streams, based on sensitivities seen on other South Asian communities, but this was rapidly adjusted as participants seemed more comfortable to attend with their spouses or family contacts, and frequently attended testing sessions in groups.

Data collection

Demographic information, as well as potential risk factors for CVH and liver disease were explored on data collection sheets (figure 30). Geographic information on individual and family origin sites, as well as educational status was collected, with the number of years of schooling used as a surrogate measure of socioeconomic status [Winkleby MA 1992]. Housing occupancy data was also collected, with the aim of understanding potential contact tracing needs in positive cases.

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Viral Hepatitis Screening

Thank you for agreeing to help us to complete this form.

Frimley Park Foundation Trust would very much like you to take a few minutes to answer the questions below so we will be able to fill out this form. We believe that the information provided will help us improve the services that we provide.

Contact numbers:

Address:

Post code:

GP's name and address:

Your Date of Birth:

Only year or age also acceptable

Are you: Male ☐ Female ☐

Are you: Single ☐ Married ☐ Widow ☐ Other ☐

What is your country of origin:

Were you born in this country? Yes ☐ No ☐ If No, then where?

What is your town and region of origin:

How long have you been in the United Kingdom for:

What is your FATHER country of origin:

What is your FATHER town and region of origin:

What is your MOTHER country of origin:

What is your MOTHER town and region of origin:

How many adults live in your household?

How many children live in your household?

How many years did you spend in school?

Have you ever had any of the following?

	Yes	No	N/A	Details
Blood transfusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Surgery abroad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, where?
Dental work abroad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Vaccination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Hepatitis vaccination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, when?
Past history of jaundice or Hepatitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A / B / C / other
Family history of hepatitis / liver disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A / B / C / other / cirrhosis
Body or ear piercing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Use of recreational/illicit drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, for how long?
Excess/ binge drinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	> 21 (M) or 14 (F) units weekly

Figure 30: Data collection sheet for participants

Participant results collection:

All patients were asked to return at one week to the same venue to pick up their results, and for any positive cases to be discussed with individuals by the clinician, with support from community leaders.

All results were screened before sessions, with positive cases separated and identified to the research-clinician, with these individuals directed to see the clinician for discussions. Provision was made for individual areas to discuss with patients if positive cases were identified.

Support was gained from local CCGs, with patients informed that any positive cases (active disease, HBsAg positive, HCV Ab positive) would be discussed with their GP for onward referral and assessment with formal blood test confirmation and specialist assessment.

Funding:

Initial funding for the study was obtained through a grant proposal written by Professor Aftab Ala (AA) and Mihaela Petrova (MP), with funding granted through the National Gilead Fellowship Award scheme to AA, and further support from Roche pharmaceuticals to assist with DBS testing kit purchasing. Further research support costs were then delivered through funding from the National Institute for Health and Research (NIHR). Researcher costs were supplemented additionally through clinical work in an NHS context.

Results:

Summary:

Testing activity was conducted over 5 sites between March 2013 to January 2015 with a total of 1005 individuals tested over 17 individual sessions (figure x), with a total of 984 individuals considered in final DBS testing analysis.

Hepatitis B surface antigen (HBsAg) was seen in just 3 individuals on DBS testing (0.3%), with HCV Ab detected in 4 individuals (0.41%), and with hepatitis B core antibody (HBcAb) detected in 93 individuals (9.5%).

Participant recruitment and testing activity:

Testing activity was conducted through the formation of a multidisciplinary team of Research Nurses from Frimley Park Hospital and Nepali community volunteers, and two clinical research fellows,

Mihaela Petrova, who assisted with initial testing over the first 500 participants, as well as myself, with the completion of testing to 1005 individuals.

The number of participants attending sessions differed with venue, and over time, with the most number of participants seen in Princes Hall in Aldershot (table x). The final session at Bracknell Open Learning Centre (Bracknell 2), was purposefully limited (n=5) to capture those individuals who we could not fit into an earlier session at the same centre, and with knowledge that we had reached our target recruitment limit. Excluding this last session, the median number of individuals tested per session (16 sessions) was 54, with an IQR of 35 to 98 (range 20-129) (figure 32)

After our first session where 20 people were tested, the following sessions had rising numbers, with some unpredictability, but staffing requirements that seemed to require a minimum of 6 members of the multidisciplinary clinical team, with 2-3 qualified research nurses needed to take DBS samples, and a staffing range overall between 6-9. This is separate to the additional requirements for Nepali translators, with a minimum of 6 Nepali community volunteers were needed to run the testing session. Smaller community sessions could be managed with 4 members of the multidisciplinary team, and ideally the same number of translators. All studies took place on weekday settings, predominantly in term-time settings, principally in relation to staffing requirements.

Session numbers were variable, and unpredictable, with large numbers arriving on occasion and sessions lasting from 09:00 to 15:00. On these occasions, not all participants could be tested, and on the last session in Princes Hall theatre (Aldershot 9), many participants had to be turned away from testing due to capacity and timing.

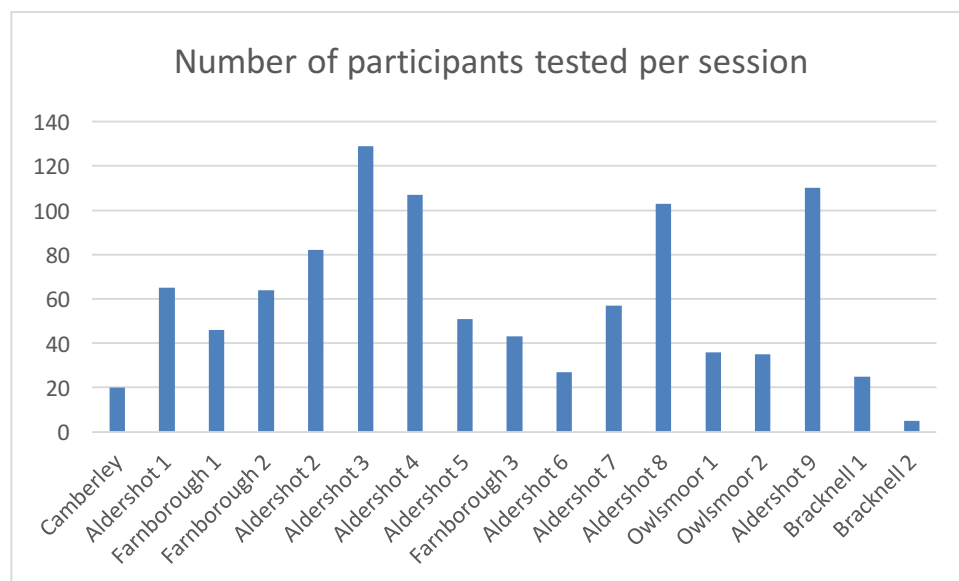


Figure 31: number of participants taking part in testing per session held over time

After our first session where 20 people were tested, the following sessions had rising numbers, with some unpredictability, but staffing requirements that seemed to require a minimum of 9 members of the multidisciplinary clinical team, with 3 nurses needed to take DBS samples. This was in addition to requirements for Nepali translators, with a minimum of 6 Nepali community volunteers were needed to run the testing session (figure 33).



Figure 32:: participant information and consent gathering with multidisciplinary research team, and Nepali community advocates

Smaller community sessions could be managed with 4 members of the multidisciplinary research team for consent and testing, and 3-4 Nepali community advocates to facilitate and translate.

All studies took place on weekday settings, predominantly in term-time settings, principally in relation to staffing requirements, with difficulties in securing staffing and members of our community team to facilitating testing.

Amongst the majority group of elderly participants in the study, there was an inability for most to read the English Patient Information Sheets (PiS), and many required help from our Nepali community volunteers in reading the Nepalese PiS and Consent forms, with significant help required from our Nepali volunteers.

In keeping with the levels of formal education recorded in our study, many of the elderly, especially elder women participants were unable to write, or sign their own name, using a “cross” in these situations to indicate their willingness to take part after the consent process.

Results delivery:

Attendance at results collection sessions were generally high, but with many attending to pick up results for friends or relatives, often having come together for testing at the session before. Around 10-20% did not attend for results collection, with these results posted to individuals to their registered (supplied) address.

Few positive results were detected in our study, and all individuals with suggested active infection attended at results collection sessions. For those individuals with HBcAb, and evidence of previous exposure to HBV, telephone conversation was conducted using our Nepali study team to inform participants if there was no representation at results sessions.

All participants were made aware of the study team contact details, and importantly of our Nepali community volunteers, who were visible in the community given their role in formal social enterprise and council initiatives.

Duplicate attendance:

Some individuals (n=10) attended twice for testing over different sessions, and this was despite early questionnaire modification (with ethics approval) to try and minimise duplicate attendance. A further participant below 18 years was inadvertently entered into testing (with reporting to the ethics board and sponsor, and negative testing results), and was also subsequently removed from final data analysis, leaving a total of 984 individuals considered in final analysis.

The role of peer-support in recruitment and testing activity:

Peer support for testing was coordinated mostly through Mr Ramji Tiwari, working with the locally established Rushmoor Healthy Living social enterprise charity, with the help of Nepali community volunteers, who were mostly ex-Gurkha veterans. Our peer-support team had all taken part in testing activity, with preceding educational presentations given regarding the rationale and aims of the study in the Nepali community, and were therefore able to help explain and promote testing to the wider community.

In view of the broader concerns regarding study advertising, word of mouth alone was used in the first half of the testing study to disseminate awareness of testing studies, and to recruit participants to attend. Face to face and telephone based discussions were conducted, with reminder SMS messaging / phone calls placed prior to testing sessions, with recipients encouraged to spread word about these testing sessions among fellow Nepali associates.

The peer-support team formed an integral part of testing activity, as well as study recruitment, being placed at key visible parts of our testing session to welcome participants, as well as their invaluable

role in supporting the consent and testing process. The senior clinician (clinical researcher/senior study clinician) was also prominent at the reception point to greet participants, as well as throughout the session, to provide a visible clinician focus to the testing event.

Word-of-mouth provided valuable participant recruitment throughout the study period. Participant numbers increased during the first part of the study, with the most numbers seen in testing sessions held in the Aldershot area, and one Nepali couple who attended after being in the UK for less than a week. However, as participant numbers dipped after the 4th and 5th sessions in Aldershot (figure x), we utilized some of the ethics approved advertising materials generated in our planning stages. A limited number of Nepali language leaflets were distributed in (peer-group) recommended Nepali shops, as well as face to face presentations at the very well attended Nepali World Cup, and the Madat Samuha group. We became aware of new existing Nepali groups as our study progressed, including the Madat Samuha group, and the regular, smaller attended groups in Bracknell and Owlsmoor, where testing numbers were expectedly low (figure x). Additional Nepali peer support was readily obtained from the leaders of these groups, with positive encouragement, and testing participation by these individuals in subsequent testing sessions.

Radio advertising was also utilized at the latter half of our study, with initially limited response to advertisements placed in the local BGWS (British Gurkha Welfare Society), before using the national BFBS (British Forces Broadcasting Service) Gurkha radio network, with a large number, and eventually unmanaged number of participants attending for testing following this, with many having to be turned away to seek GP testing due to capacity limitations.

Overall, whilst we did not collect formal data on participant recruitment, word of mouth in the community seemed the most powerful driver of attendance, with positive support for testing in those who were attending.

Demographics:

The median age of participants was 66 years, mean 63 years (IQR: 60 to 70 years, range: 19-86 years), with 525 female participants (54%). The majority of participants were elderly, with an age distribution which was skewed towards an elderly population (fig 33).

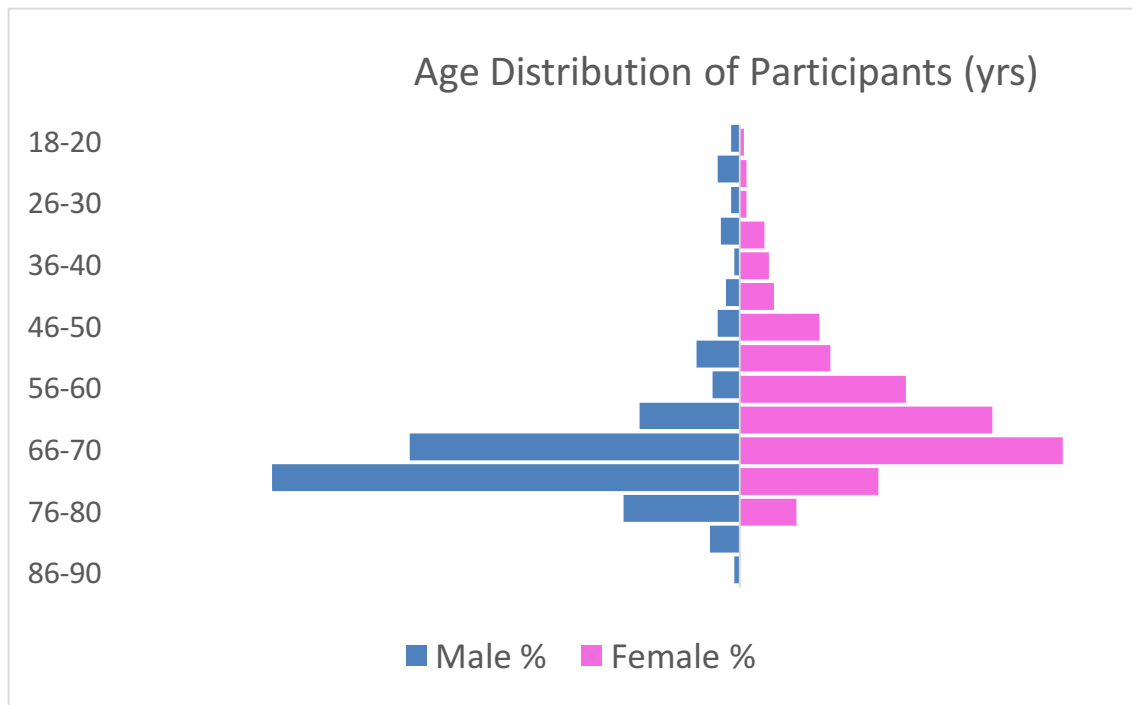


Figure 33: Pyramid chart showing age distribution of male and female participants

The majority of male participants were elderly, with female participants at greater representation between 45-60 years.

Of note, many of the participants had recorded date of births as 01/01 (Day,month), with a lack of priority and recall that is afforded to age in many of the participants, reducing the accuracy of age measures, and increasing the need for careful documentation of personal identifiable details in the testing activity studies.

Geographic origin:

The overwhelming majority of participants were born in Nepal, with 5 who were born in Hong Kong, and one in Pakistan. No UK born Nepali born individuals were identified in the study.

District of origin data was available on 680 individuals, with 31 districts identified. A population map is presented in figure 34, table 16.

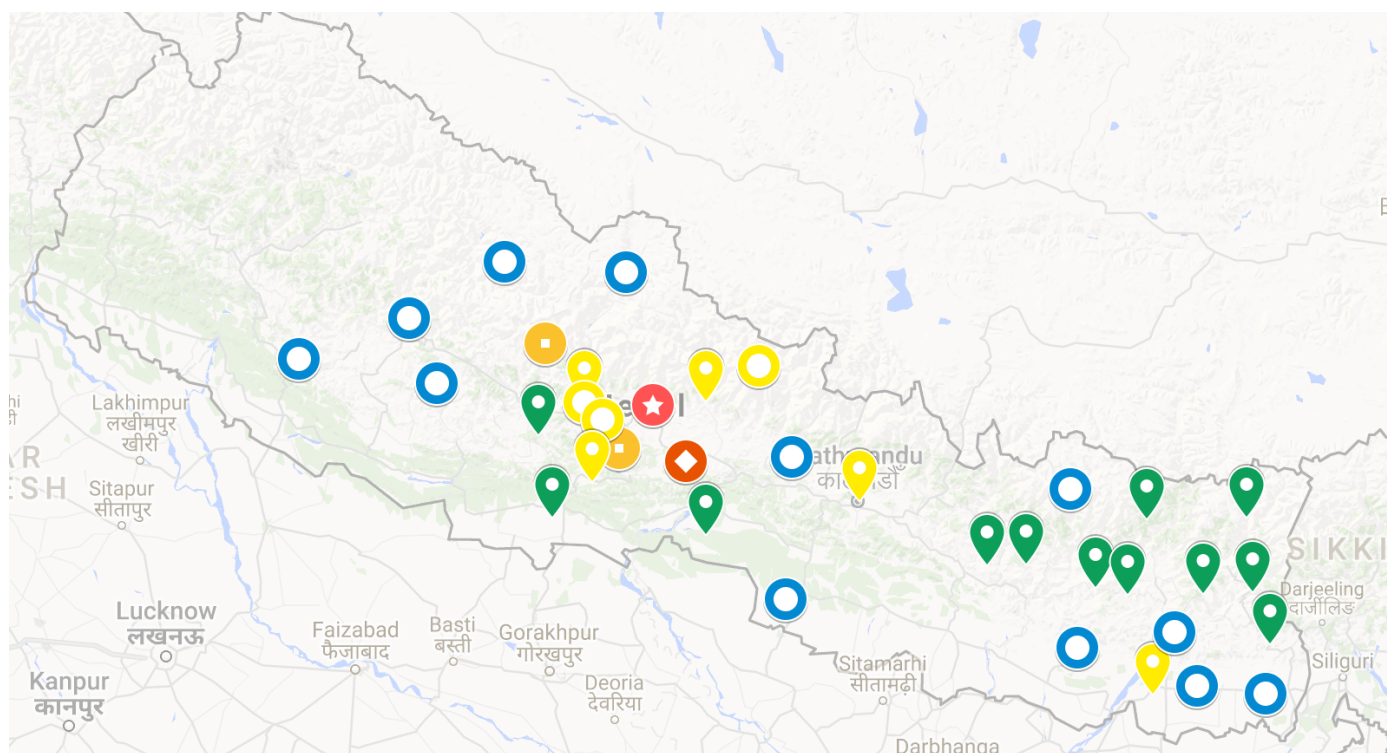


Figure 34: Map demonstrating the origin points of testing participants; red = higher concentration of participants (close to 12%, Kaski region), with decreasing frequencies: dark orange = 8%, orange = 4%, yellow = 2 percent, green = 1%, blue = 0-1% of participants

District	Number of Participants	Percentage
Dolpa	1	0.15
Mustang	1	0.07
Rolpa	1	0.07
Rukum	1	0.07
Dhading	2	0.15
Parsa	2	0.15
Surkhet	2	0.15
Udayapur	2	0.15
Dhankuta	5	0.37
Morang	4	0.30
Jhapa	7	0.52
Solukhumbu	5	0.37
Ramechhap	7	0.53
Rupandehi	7	0.53
Panchthar	8	0.61
Chitwan	12	0.91
Gulmi	12	0.92

Bhojpur	14	1.08
Ilam	15	1.17
Taplejung	11	0.87
Khotang	17	1.36
Okhaldhunga	17	1.37
Sankhuwasabha	16	1.31
Terhathum	13	1.08
Kathmandu	24	2.02
Palpa	21	1.78
Lamjung	25	2.17
Gorkha	34	3.00
Sunsari	27	2.44
Parbat	34	3.17
Baglung	28	2.67
Myagdi	44	4.34
Syanga	39	3.96
Tanahun	71	7.55
Kaski	151	16.74
Total:	680	

Table 15: participant distribution, and relative percentage contribution according to district

Education: years of formal schooling

The median number of years of schooling reported by all participants was 0 (average 2.1 years), with an interquartile range of 0 to 3 years; range 0 to 15 years.

Looking at those individuals below 40, the median number of years of schooling across both males and females was 10 years. In those between 40 to 50 years, the median number of years of schooling reported was 4 years, with a corresponding median value of 10 years (average 9.4 years) in male participants, and a median value of only 3 years amongst female participants in the same age group between 40 to 50 years.

In those between 50 to 60 years, the median number of years of schooling was 0 (average 2.7 years), but with a median value of 10 years among male participants (range 0 to 20, average 8.8 years). In female participants in this group, 17/19 (17%) women reported some schooling, with 11 (11%) of these women having 5 years or more of formal schooling.

This trend continues in participants between 60 –70 years, with a median value of 0 years (average 1.5 years), and with an average range of schooling of 0 years, but with an average value of 2.9 years

amongst male participants (median of 0 years). Above 70, few participants (all male) reported some years of formal schooling, occasionally with training that they had received in neighbouring India.

Length of stay in UK:

Length of stay information in the UK was available on 930 individuals, with a median residence of 36 months in the UK (mean 41 months), IQR 24 to 48 months (range: 1 to 420 months (36 years)). Over 85% of participants (801/931) included in the study had been in the UK for less than 5 years, with 18% (164/931) of the tested community who had arrived in the past year (figure 35).

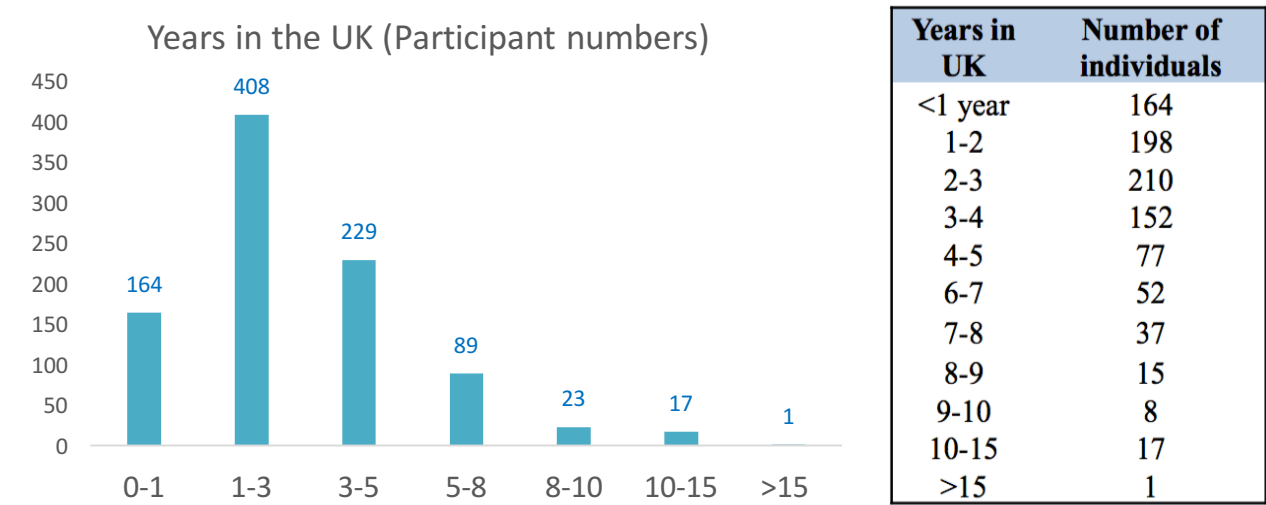


Figure 35: the majority of those tested had been in the UK for less than 5 years.

Potential risk factors:

A summary of the potential risk factors identified is presented in table x. Few (<10%) had received blood transfusions in the past, although rates of reported surgery abroad in the group was high at 33%. High proportions of the group reported previous vaccinations and dental work abroad, although less (8.8%) were aware of having received a hepatitis vaccine specifically. A history of liver disease was identified in around 7% of participants, with a family history of liver disease that was mentioned in around 9% of responses.

Piercings (outside the UK) were identified in 90% of the Nepali participants, with high representation among men and women. During testing sessions, participants recounted cultural traditions of most babies having their ears pierced shortly after birth, regardless of gender, with concerns one would envisage from a sterility perspective in how these piercings were delivered in Nepal in such a wide scale, and over such a lengthy time period. Few disclosed recreational drug use, and given the busy

nature of the sessions, as well as Nepali advocates working with the study team, recreational drug use and alcohol use may have been more uncomfortable for participants to discuss. Regardless of this, alcohol intake above recommended levels was identified in 17% (166) participants, with 60 (34%) of these individuals' female (table 17).

	Total (events occurred)	Male	Female	HBsAg	HCV Ab	HBcAb
Blood transfusion (973)	75 (7.7%)	42	33	0	0	6 (8%)
Surgery Abroad (979)	327 (33%)	127	195	0	1	29 (8.9%)
Dental work abroad (976)	403 (42%)	148	250	1	1	38 (9.4%)
Vaccination (973)	698 (72%)	318	373	3	2	67 (9.6%)
Hepatitis Vaccination (962)	85 (8.8%)	40	43	0	0	6 (7%)
Past hx of jaundice (975)	73 (7.5%)	44	28	0	0	8 (11%)
Family history of liver disease (976)	95 (9.7%)	42	52	1	0	10 (11%)
Body/ear piercing (980)	882 (90%)	356	512	3	4	80 (9%)
Recreational/illegal substances (979)	20 (2%)	11	9	1	1	18 (11%)
Alcohol (978)	166 (17%)	106	60	1	1	18 (11%)

Table 16: Potential risk factors (n=total number of participant responses available), and positive findings among participants

Statistical analysis:

All data collected was categorical, with analysis conducted on Microsoft Excel, as well as R Studio, with collaboration with the Clinical Informatics Group at the University of Surrey.

Multiple logistic regression analysis was chosen to explore relations between the variables collected (figure x), and to reduce the effects of possible confounders during analysis. Statistical association with each variable was assessed through p-values, z-values (regression coefficient) and odds ratios. Further statistical significance testing was explored through Chi-Square testing and the Fisher's Exact

test, with particular application of the Fisher's Exact test given the low absolute numbers of HBsAg and HCV Ab cases detected during the testing study.

Logistic regression analysis provides odds ratios, as well as probability assessments of the relationships between the variables collated and CVH results. However, the model relies on the assumptions that the variables considered are linear and independent, whilst in reality, some of the potential risk factors and demographic factors may have some correlation, with additional modelling errors that arises from data drop-out in the fields collected.

Data drop-out:

All participants had documented results for their HBV and HCV status, but with some drop-out of data fields in most of the recorded fields (table 18). The most affected field was in the recording of geographic place of origin of participants, with a loss of data recording in 304 individuals. This error originated during one of the early testing sessions, where staff to participant levels were low, with this field missed off in data recording over 3 sessions by some of the research team, before being subsequently rectified for subsequent sessions.

	Sex	Age	Country of Origin	Born in	District	Months in UK
Data Loss (%)	13 (1.3%)	3 (0.3%)	1 (0.1%)	2 (0.2%)	304 (31%)	72 (7.3%)
	Adults in household	Children	Years spent in school	Blood transfusion	Surgery abroad	Dental work
Data Loss (%)	20 (2%)	151 (15%)	64 (6.5%)	10 (1%)	5 (0.5%)	9 (0.9%)
	Vaccination	Hep vaccine	PHx of jaundice	FHx of jaundice/LD	Body/ear piercing	drugs /alcohol
Data Loss (%)	10 (1%)	30 (3%)	8 (0.8%)	9 (0.9%)	4 (0.4%)	5 -7 (0.5-0.7%)

Table 17: data loss (individuals) during results collection; 31% of District level data was not captured

Statistical analysis, and in particular multiple logistic regression is likely to have been affected by this, with multiple logistic regression analysis conducted with and without the inclusion of these data fields in the final analysis of HBcAb status (as below).

Hepatitis B & C testing results:

Rates of HBsAg and HCV Ab detection were low across the 984 individuals tested. HBsAg was identified in 3 (0.3%) individuals through DBS testing, with all individuals' male, and aged between 60 to 70 years. HCV Ab was seen in 4 individuals (0.41%), in 2 males and 2 female participants, aged between 60 to 70 years.

No cases of dual HBsAg and HCV Ab were identified, although there was some cross-over in chronic HBV exposure, with one individual with HCV Ab also demonstrating HBcAb on DBS testing suggesting previous exposure.

All identified participants were offered formal clinic follow-up, with formal correspondence sent to the participants GP (with written, and verbal consent at our results sessions) for onward secondary care referral.

HBsAg positive participants:

All 3 individuals with HBsAg positivity attended initial clinic visits, with baseline characteristics as identified in table 19. At first clinic attendance, the first individual (B010) had no detectable DNA on testing, indicating a low replicative state. The second (B372) had a HBV DNA load of 250iu/ml, in keeping with a low replicative state, but subsequently failed to attend his follow-up appointments despite reminder correspondence. The third participant (B610) also had low levels of viral replication on testing, with HBV DNA levels of 55 iu/ml, with normal Fibroscan assessment of 5kPa (table 19).

Participant ID	Sex	Age	HBsAg	HBV DNA levels / further assessment
B010	Male	66	HBsAg +	HBV DNA undetectable
B372	Male	66	HBsAg +	HBV DNA 250 iu/ml
B610	Male	70	HBsAg +	HBV DNA 55, normal Fibroscan

Table 18: HBsAg positive results, and demographic information

In keeping with the low number of positive cases, logistic regression analysis did not suggest any probable relations to the variables measured, and Fisher's Exact testing with these variables (excluding District data) also did not suggest any associations, with p-values 0.3 to 1 (Appendix).

HCV Ab positive participants

4 individuals were identified on DBS with HCV Ab, with HCV RNA testing that was performed via DBS samples. 2 individuals were female, with an age range between 65 to 75 years (table 20).

All samples tested negative for HCV RNA on DBS testing, with clinic invitations issued to all patients via their GP, with formal primary care referral.

Participant ID	Sex	Age	HCV Ab	HBV status	HCV RNA assessment
B388	Female	67	HCV Ab	HBcAb negative	HCV RNA negative
B602	Male	74	HCV Ab	HBcAb negative	HCV RNA negative
B841	Female	66	HCV Ab	HBcAb POS	HCV RNA negative
B871	Male	70	HCV Ab	HBcAb negative	HCV RNA negative

Table 19HCV Ab positive results, and demographic information

Clinic follow-up attendance for HCV Ab positive patients were lower, with only two patients attending for formal assessment, with no significant evidence of advanced liver scarring (fibrosis, portal hypertension), from bloods and ultrasound assessment on these individuals.

As expected statistical analysis did not suggest statistical association through logistic regression or Fisher's Exact testing (Appendix x).

Adults per household / Children – contact tracing implications

Overall, the median number of adults per household in the Nepali community was 2 (average 3, range 1-10), with a median of 0 children residing per household (range 0 – 6).

For those 3 individuals found to HBsAg positive, data was available on 2 participants, with 2 adults (including the affected individual) living in the same accommodation, and no children living with these individuals.

Of the 4 individuals identified with HCV Ab positivity, 2 to 6 individuals (including the affected participant) lived in their home accommodation, with one individual living with 2 children.

Hepatitis B core antibody (previous HBV exposure):

In total, HBcAb was identified in 91 (9.25%) participants, with HBsAg positivity identified in 3 of these individuals as discussed above.

The median age of these individuals was 68 years (range 22-84 years, IQR 64-72 years; mean 67 years), with 58 (64%) of these individuals of male sex (table 21

	Sex M (%)	Age (Median)	District (ordered)	Months in UK (median)	Years spent in school (median)	Blood transfusion	Surgery abroad (%)	Dental work (%)	Vaccination (%)	Hep vaccine (%)	PHx of jaundice (%)	Body/ear piercing (%)	alcohol (%)
HBcAb +	58 (64%)	68	Kaski 27 (49%) Myagdi 9 (16%) Tanahun 4 (7.3%)	36	0	3 (3.3%)	13 (14%)	23 (25%)	36 (40%)	3 (3.3%)	5 (0.5%)	82 (91%)	16 (17.6%)

Table 20: Table: demographics and characteristics (potential risk factors) of individuals identified with Hepatitis B core antibody

Multiple logistic regression analysis was conducted to look for possible relations between a positive HBcAb status and potential risk factors collected, with statistical association identified with “male gender”, and “years spent at school”.

Logistic regression analysis was conducted initially with the inclusion of “district” data, but with the resulting addition of a significant number of NA values to the modelling, given the loss of district level data collection during initial testing studies. Logistic analysis was therefore conducted with and without the addition of district level data (table 22 A/B,) to assess for any variance in the two models.

Coefficients:				
	Estimate	Std. Error	z value	P value
(Intercept)	-1.70E+00	1.46E+00	-1.166	0.2438
GenderI	1.40E+00	1.18E+00	1.181	0.2377
Gender Male	1.02E+00	3.24E-01	3.156	0.0016 **
Age	-3.72E-03	1.70E-02	-0.219	0.827
DistrictBhojpur	2.22E-01	1.31E+00	0.17	0.8651
DistrictChitwan	-1.65E+01	2.47E+03	-0.007	0.9947
DistrictDhading	-1.65E+01	4.59E+03	-0.004	0.9971
DistrictDhankuta	-1.67E+01	6.52E+03	-0.003	0.998
DistrictDolpa	-1.64E+01	6.52E+03	-0.003	0.998
DistrictGorkha	-1.45E+00	1.21E+00	-1.194	0.2325
DistrictGulmi	-1.64E+01	1.96E+03	-0.008	0.9933
DistrictIlam	-1.65E+01	1.62E+03	-0.01	0.9919
DistrictIlam	-1.70E+01	4.57E+03	-0.004	0.997
DistrictJhapa	-1.63E+01	2.57E+03	-0.006	0.9949
DistrictKaski	-2.33E-01	7.45E-01	-0.313	0.754
DistrictKaski	-1.74E+01	6.52E+03	-0.003	0.9979

DistrictKathmandu	-7.71E-01	1.31E+00	-0.589	0.5558
DistrictKhotang	4.32E-01	1.06E+00	0.408	0.6835
DistrictLamjung	3.96E-01	9.24E-01	0.429	0.6683
DistrictMorang	-1.61E+01	3.05E+03	-0.005	0.9958
DistrictMustang	-1.73E+01	6.52E+03	-0.003	0.9979
District Myagdi	1.37E+00	7.80E-01	1.763	0.0779 .
Districtn/a	2.20E-01	6.89E-01	0.32	0.749
DistrictOkhaldhunga	-1.65E+01	1.72E+03	-0.01	0.9923
DistrictPalpa	-4.55E-01	1.27E+00	-0.358	0.7203
DistrictPanchtar	-1.65E+01	6.52E+03	-0.003	0.998
DistrictPanchthar	-1.63E+01	2.60E+03	-0.006	0.995
DistrictParbat	-4.19E-01	1.00E+00	-0.418	0.676
DistrictParbat	-1.65E+01	6.52E+03	-0.003	0.998
DistrictParsa	-1.75E+01	6.52E+03	-0.003	0.9979
DistrictRamechhap	-1.67E+01	2.64E+03	-0.006	0.9949
DistrictRukum	-1.55E+01	6.52E+03	-0.002	0.9981
DistrictRupandehi	-1.59E+01	2.45E+03	-0.006	0.9948
DistrictSankhuwasabha	-1.69E+01	1.89E+03	-0.009	0.9929
DistrictSunsari	-6.53E-01	1.26E+00	-0.519	0.6041
DistrictSurkhet	-1.63E+01	4.61E+03	-0.004	0.9972
DistrictSyanga	-1.48E+00	1.23E+00	-1.207	0.2273
DistrictTanahun	-6.78E-01	8.96E-01	-0.757	0.449
DistrictTaplejung	-1.65E+01	2.26E+03	-0.007	0.9942
DistrictTerhathum	6.85E-02	1.33E+00	0.052	0.9589
DistrictUdayapur	-1.56E+01	6.52E+03	-0.002	0.9981
Months.in.UK	4.07E-03	5.34E-03	0.761	0.4464
Adults.in.household	-1.02E-01	9.29E-02	-1.1	0.2712
Children	-1.61E-01	2.25E-01	-0.716	0.4741
Years.spent.in.school	-1.26E-01	5.60E-02	-2.24	0.0251 *
Blood.transfusion	-4.48E-02	5.44E-01	-0.082	0.9344
Surgery.abroad	-1.65E-01	2.97E-01	-0.557	0.5777
Dental.work	2.70E-01	2.82E-01	0.957	0.3386
Vaccinationy	-2.81E-01	3.33E-01	-0.843	0.399
Hep.vacciney	-1.50E-01	5.50E-01	-0.272	0.7857
PHx.of.jaundice	1.38E-01	5.41E-01	0.254	0.7993
FHx.of.jaundice.LD	6.97E-02	4.26E-01	0.164	0.8701
Body.ear.piercing	-2.16E-01	5.11E-01	-0.423	0.6723
drugs	9.83E-01	7.71E-01	1.274	0.2025
alcohol	6.85E-02	3.92E-01	0.174	0.8615

Table 21 A : Logistic regression analysis with the inclusion (A) and exclusion (B) of District level data

Coefficients:				
	Estimate	Std. Error	z value	P value
(Intercept)	-1.801819	1.201755	-1.499	0.13379
GenderI	0.889918	1.11072	0.801	0.42301
GenderM	0.954461	0.308318	3.096	0.00196 **
Age	-0.006964	0.016649	-0.418	0.67574
Months.in.UK	0.002371	0.004739	0.5	0.61688
Adults.in.household	-0.091073	0.088982	-1.023	0.30607
Children	-0.19525	0.213116	-0.916	0.35958
Years.spent.in.school	-0.1254	0.05465	-2.295	0.02176 *
Blood.transfusion	-0.103508	0.51566	-0.201	0.84091
Surgery.abroad	-0.047528	0.280544	-0.169	0.86547
Dental.work	0.154459	0.264726	0.583	0.55958
Vaccination	-0.03777	0.307957	-0.123	0.90239
Hep.vaccine	-0.268196	0.508622	-0.527	0.59799
PHx.of.jaundice	0.044834	0.510651	0.088	0.93004
Body.ear.piercing	-0.077951	0.453025	-0.172	0.86338
drugs	0.84116	0.681712	1.234	0.21724
alcohol	-0.067874	0.335341	-0.202	0.8396

Table 22B: Logistic regression analysis with the exclusion of District level data

Logistic regression analysis with and without this (district level) data identified two statistically significant associations between HBcAb status and male gender, as well as the number of years spent at school. For male gender, a positive correlation towards HBcAb status was suggested, with a p-value of 0.0016, a z-value of 3.16 (table 21), and an Odds ratio (OR) of 2.60 (confidence interval (CI) 1.42 – 4.78); with the OR calculated with the exclusion of district level data.

For the number of years spent in school, a negative correlation was suggested, with a p-value of 0.025, a z-value of -2.30, and an OR 0.88 (CI 0.78-0.97), with fewer years of schooling seemingly associated with HBcAb status (figure 37).

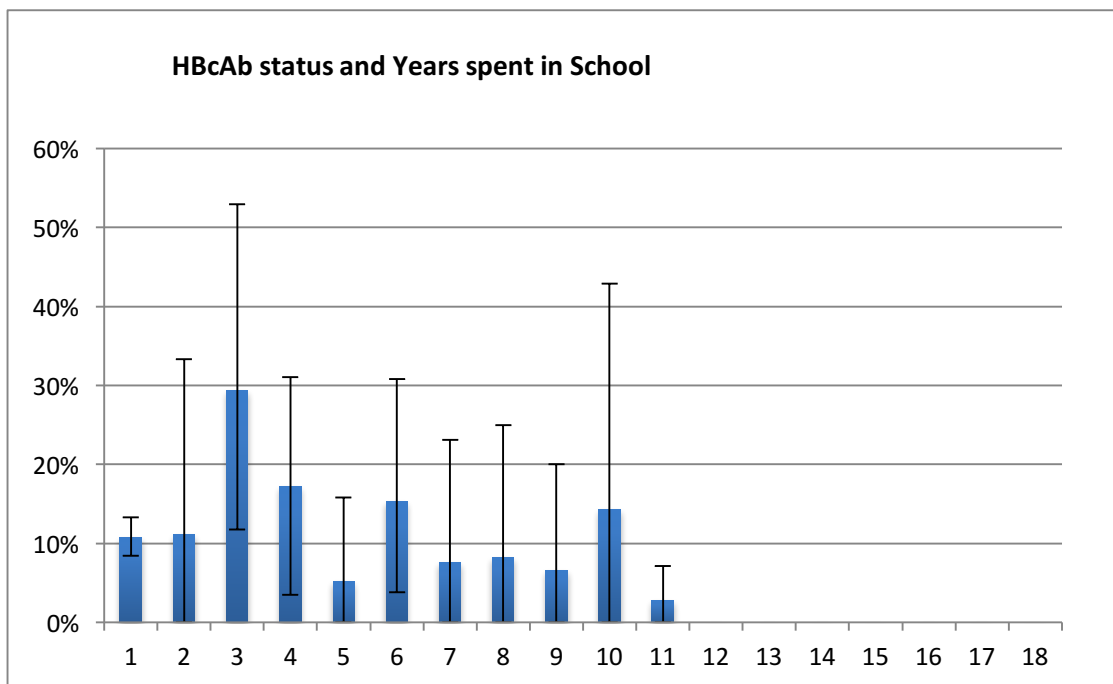


Figure 36: HBcAb positivity (represented as a percentage; with 0 years taken as reference), and the number of reported Years spent in formal schooling

Although the initial district level regression analysis suggested that there may be some association between HBcAb status and participants from the Myagdi region (table 22A), this did not reach statistical significance ($p=0.0779$), and with a loss in data fields.

Key Outcomes:

We developed a successful strategy to engage with close to 1000 individual members of the local Nepali community. We utilized the help and integral support of community advocates in the Nepali community to achieve testing in large numbers, with close ties formed with key respected members of the Nepali community.

Nepali community advocates provided peer support for testing, disseminating awareness of the study, as well as the rationale and health benefits to the community through taking part. Despite limitations that we faced in advertising, word of mouth proved a strong medium to disseminate information, and to achieve a good attendance at testing sessions, with all participants happy to take part in the study on attendance. Within the limited advertising strategies assessed, radio adverts placed on the national BFBS Gurka network achieved a high uptake of participants, with many participants having to be sign-posted to GP services due to the overwhelming attendance. Stall-based presentations to a mixed

Nepali crowd at the large Nepali World Cup was received with interest from other community groups in the Nepali community, but with little suggestion of direct impact anecdotally. My presentations and discussion at Nepali community groups, with direct translation and support from senior Nepali members of each group was met with positive support, with many individuals seen shortly after in testing sessions as a result.

The majority of the group were unable to read and write in English, with many of the elderly, especially Nepali women demonstrating a functional illiteracy in Nepalese as well. Language remained a barrier through the study process, but with good levels of engagement, attention and interest given towards healthcare staff during presentations and discussions which were translated in real time.

The Nepali community is heterogeneous, with multiple community based sessions that can provide access to meet with different groups of the local population, but with no central organisation, or oversight of these activities, and no universal route to access. Testing sessions were developed iteratively, with new groups and locations identified during our study through the enquiries of our Nepali advocates, as well as the research team.

DBS testing was well received, with no practical difficulties encountered with delivering this in community settings, and no concerns raised from the organisers of the multi-purpose community centres used.

Absolute rates of active CVH for HBsAg (0.3%) and HCV Ab (0.41%) was low, and comparable to the rates seen in the background UK population (HBsAg 0.3% (UK), HCV 0.4% (England) [PHE 2013]). On initial assessment, rates of viral replication were low in HBV, and with no RNA detected on HCV Ab testing, suggesting previous, cleared HCV infection.

Rates of HBcAb exposure however are high, at 9.25%; suggesting HBV exposure in Nepal, and raising the concern for any additional cases of HBsAg that may have been missed in the community in those who did not take part in testing studies.

Multiple logistic regression analysis suggests a statistical association between male gender, and lower education status with HBcAb positivity, and it may be that there is some geographic variation associated towards HBcAb status, although without reaching formal statistical analysis cut-offs, and with significant data gaps in the collated geographic district data from many patients.

Nearly all participants were exposed to presumed non-sterile piercings at a young age, with high proportions also exposed to surgical and dental procedures, but without a noted association to HBcAb or CVH, and with low absolute levels of active disease. Alcohol was mentioned as a risk factor in 17%

of participants, with a third of these being women. Given the communal nature through which this information was gathered, it may be that this is an underrepresentation, with concerns over alcohol risk modification long term.

Initial clinic uptake for follow-up of patients identified with HBV was high, but with subsequent missed hospital appointments, and with a lower attendance among patients identified with HCV Ab profiles.

Chapter Summary:

We developed a successful engagement strategy with members of the recently arrived Nepal community. Community volunteers and peer support were instrumental in the implementation of CVH testing, with a dedicated multi-disciplinary research team leading CVH testing in community based settings.

There was clear evidence of racial tension in the local community through the publicity of far-right groups during our testing study. This had impact on our study recruitment, but more importantly raises fears of social exclusion in the recently arrived Nepali community. Despite this, the local community were keen to engage in testing activity, and in learning more about liver disease in keeping with focus group findings.

Active CVH rates are very low in the tested cohort, but with significantly elevated rates of previous HBV exposure that raise the need for ongoing study to understand this risk, and possible higher HBV risks in the Nepali community.

Chapter 7

Discussion

Chapter 7 Discussion and Conclusions:

Introduction:

The aims of this study were to understand the CVH risks that exist in the recently arrived Nepali community, and the barriers that exist towards CVH testing in migrant communities across the health system.

The following chapter presents an overview of the key arguments raised and identified through the narrative of this thesis, and its principal findings. The implications of these findings, and their grounding in existing literatures is also presented, with a summary of the key limitations of the study, and areas to explore in future studies to further develop CVH testing access and provision to migrant communities.

Principal findings:

The political, social and health impact on migration and the recently arrived Nepali community:

Politically, migration continues to feature at the highest level, with contribution to the recent EU referendum and to UK elections during the timespan of this thesis [Independent June 2017]. Rising nationalism and anti-migrant sentiment is being seen across Europe, coupled with unprecedented rates of migration that continue worldwide due to complex political, military, environmental and economic pressures. Socially, migrants may face anti-migrant sentiment within their environment, with these challenges clearly demonstrated during our work with the Nepali community. And despite the high profile public support for UK settlement rights for the Gurkha community, they now face many of these challenges here in the UK after their arrival [Telegraph February 2011], with clear evidence of anti-Nepali sentiment expressed during our time with the community.

As such, migrant communities may face many negative determinants of health across socioeconomic and environmental conditions, with impacts on social and community networks that may negatively impact health access and engagement [WHO 2010]; with these concerns evident in the newly arrived Nepali community.

Chronic Viral Hepatitis (CVH) risks globally are substantial, with more deaths attributable to CVH than that seen due to HIV, and comparable to that seen with tuberculosis [WHA September 2017, Lancet September 2017], with risks that are largely unknown in the newly arrived Nepali community.

Developing an intervention to understand the CVH risks in the Nepali community is therefore important, with the need for direct assessment of this risk, as well as understanding of the barriers that exist more broadly in migrant communities.

Policy (macro-level) analysis of NICE CVH testing recommendations – achieving policy priority

NICE CVH recommendations provide comprehensive guidance on at-risk groups to be offered testing, with Primary Care the principal group charged with delivering these community testing interventions, particularly in migrant communities. These recommendations feed into the global targets established during the development of this thesis, with the WHO published goals of CVH eradication by 2030, for which effective policy implementation towards CVH case-finding is crucial. Effective policy implementation would provide an effective method to achieve widespread CVH testing, including testing access in the newly arrived Nepali community.

The history of CVH testing uptake is however poor, despite previous national policy endeavours in the UK, with particular concerns of policy awareness and uptake in primary care. Utilising the Policy Prioritisation Framework as developed by Shiffman and Smith, and as adapted by Walt and Gilson, several gaps are apparent that are likely to affect policy uptake and implementation across several levels:

- Actor Power: The actors involved in policy development are supportive of its' objectives and implementation, but without clear leadership that is identified, and with policy that was designed largely in a top-down approach, with little evidence of community involvement, incentive or dedication towards testing practice.
- Ideas: there are uncertainties that exist in our understanding of CVH risks, and how to best achieve testing. The internal community remains committed to endeavours to improve current activity, but the view and commitment at the primary care (ground) level is unclear. At the external frame, the public are likely more aware of CVH through recent (positive) initiatives and developments, but concerns of stigmatisation remain, particularly in migrant communities.
- Context: CVH testing policy was developed with high-level political support, with national oversight that was developed at the same time through the National Liver Strategy. The introduction of the Health and Social Care Act does not appear to have not been predicted, or factored into CVH policy, with the subsequent loss of the National Liver Strategy. The recent introduction of the ODNs, and central role played by NHS England may provide greater coordination and oversight of CVH case-finding and treatment going forward.

- **Issue Characteristics:** there is ongoing uncertainty in the measures used to currently monitor CVH testing, with no established oversight (coordination) of testing activity. The severity of CVH can be assessed through surrogate markers in hospital statistics, but there remains gaps in our understanding of the effective (practical) routes to achieve testing uptake in heterogeneous at-risk groups, including migrant communities. Previous (positive) cost-effectiveness assessments of CVH testing are likely to be improved in consideration of the vast improvement in treatment options and treatment uptake.
- **Outcome:** Whilst there are clear recommendations to primary care and community groups to action testing in migrant groups and other at-risk groups, there is little in the way of practical direction as to how this can be achieved, reducing the authoritative decisiveness of policy. Dedicated resources to facilitate testing are difficult to find, with a lack of financial and human resources that are additional or identified from policy. The development of the newly formed ODNs, and recent drives in the wake of DAA successes may however act as a resource to facilitate policy objectives.

Focus Group studies in the Nepali community: the awareness, knowledge and perception of liver disease:

Common themes are identified across the four Nepali focus groups, as well as conflicting views that are seen within and between groups.

Awareness of disease: Awareness of liver disease is high across all 4 focus groups, and is synonymous with the clinical manifestation of jaundice in the vast majority of participant discussions. Uncertainties and conflict though exist towards the cause of liver disease; why it occurs, and how one can protect oneself from the onset of disease:

“In my opinion anybody can get it. It might get for children. I have seen young friends also did get liver disease. If you do not care, it get to everybody. It goes beyond gender and age and reach everybody (participant 1); Taking care with food matters long term, even if jaundice has happened before....is this true? (participant 6) [Male FG <30]”

Awareness of disease is frequently presented in personal or first-hand reflection, and this may relate to prior experiences with hepatitis A as a transient illness in Nepal.

Knowledge of specific aetiologies is limited, and whilst viral hepatitis is mentioned a specific agent by some participants, it is mentioned infrequently, and often with a plurality of beliefs that place a viral pathogen alongside possible food and water pollutants, which remain the principal agent associated with liver disease across all focus groups. There is considerable uncertainty among participants though how to define liver disease, and the potential agents responsible for disease. Despite the

heterogeneity in viewpoints, there is equally a degree of certainty expressed in defining these often opposing views.

Intrinsic and extrinsic factors are listed as potential causes of disease, with self-control and responsibility that are expressed as controlling factors to protect against, and manage disease:

“ [...] It is necessary to take care on food. It is caused by negligence (participant 1); “[...] Because of not taking care in their food habit it occurs (participant 2) [Male FG<30]”.

“When we see the jaundice from a Nepalese perspective, it is transmitted through stool, urine and food (Participant 3) [Male FG>30]”.

Spiritual associations feature in discussion alongside dietary exposure and a loss of traditional cooking or eating practices as causes of disease, with the additional role of self-control and responsibility placed as factors that may promote or limit disease:

“ [...] It is necessary to take care on food. It is caused by negligence (participant 1); “[...] Because of not taking care in their food habit it occurs (participant 2) [Male FG<30]”.

“When we see the jaundice from a Nepalese perspective, it is transmitted through stool, urine and food (Participant 3) [Male FG>30]”.

Knowledge of potential treatment strategies is limited in the group, and there is the strong suggestion that many view herbal and traditional strategies as a trusted “first-source” of therapy, with particularly negative perspective portrayed from their experiences in Nepal.

Perceptions towards the severity of liver disease, and the concern of liver disease in the community suggests this to be a feared disease, with particular futility presented by some of the older female participants once liver disease was diagnosed, often at a late stage.

In addition, many express concern in trying to understand how to protect themselves from this severe illness, with uncertainties that exist within the heterogeneous range of aetiologies and risks presented in the four focus groups. As such, liver disease is expressed as a disease area of concern, and an area to engage in for education and management.

Perceptions towards stigma are raised by individuals in each focus group, but with younger female participants expressing particular concerns towards the role of alcohol and prostitutes in liver disease. Many of the factors that suggest stigma are likely to be external factors that are prevalent in society at large, but there is likely to be a degree of internalisation of these stigmatising factors in how CVH is viewed, with some of the younger female participants identifying differences in how the English, Chinese and Nepali interact and view one another:

“I think more English and Chinese people have it than Nepali. They use more perfume and take less shower. They smell badly. They point to us but I say we are more healthy than them (Participant 2) [FemaleFG<30].

Despite this, and the alliance towards traditional therapies, the community seem engaged with learning more about liver disease, and interacting with primary care in particular. There is also understanding, particularly in the older female group that modern medicine and life in the UK can offer many new and modified therapy approaches that would not be available to them in Nepal.

Qualitative studies in primary care: the awareness, perception and practice of CVH testing:

Qualitative studies in primary care suggest a low priority currently afforded to CVH testing overall, with particular deficits in testing in migrant populations.

Most GPs reported awareness of CVH testing activity in relation to clinically driven scenarios, and as reactive testing activity to jaundice, or deranged liver function tests. Awareness of testing in antenatal settings seems well adopted, but with the simultaneous identification that most of this testing activity is performed by associated midwives.

The main group considered to approach for CVH testing are those with an injecting drug use history; but with difficulties that practitioners report in engaging with these individuals for testing, as well as perceived blurring of responsibilities and communication between primary care services and drug and alcohol services who may also interact with these individuals.

There is lack of any systematic or structured approaches to identify at-risk groups in practices, with resource pressures cited as one of the reasons behind this:

“And we don’t always know who the at-risk groups are, and we’re not constantly asking the question. We’re all so busy, that to actually go through a whole load of screening questionnaires. (pause) If we’ve missed it on the new-patient check, we’ve probably missed it... (Participant 8)”.

Knowledge of formal CVH testing policy seems limited and likely absent from focus group discussions. This may relate to the broader work and resource pressures that GPs feel, but more likely seems related to the low priority and resistance that is presented towards CVH testing activity overall.

Chronic CVH is portrayed as poorly, or incorrectly misunderstood, particularly in reference to acute and chronic CVH, and the casual way in which CVH is identified for patients, with no corresponding reference during discussions as to the linkage of care that is required for these individuals to have been treated.

CVH is therefore framed principally as a benign condition, with little mention of the morbidity and mortality complications that CVH can lead to, particularly in view of cirrhosis and HCC. None of the GPs across the three GP practices had any current system of CVH case-finding.

Perceptions towards CVH testing was principally discussed with reference to the harm that testing could have on patients and their immediate family, as well as the difficulties that CVH testing poses to GPs who may be unfamiliar with this activity, and who appear fearful of raising issues of prejudice and racism in specific reference to testing in migrant communities:

“there is kind of a bit of a barrier” (nods of agreement in room); “especially if you’ve got a population with a cultural or language barrier already, they may not take it well for something unrelated, and it can cause offense [...] (Participant 7)”.

“is it not going to be judged again....., as being prejudiced against one racial group (Participant 6)”.

Only amongst the military practitioners was the concept of testing in migrant groups mentioned, but with the stated abandonment of this testing activity due to concerns of acting in, or being seen in a prejudice manner.

Capacity and resource pressures are a significant issue and concern among all participants, but the overwhelming expression as a group is to place CVH testing as poorly understood, and a low priority to engage with in primary care:

“I’d say that it is a complete waste of money, because it’s all being done anyway. And we screen all the antenatals anyway don’t we?”; “You know, It’s just one of those stupid things isn’t it? (Participant 2)”

Developing a community-based intervention to assess CVH risks in the Nepali population:

We developed a successful community-based CVH testing initiative in close to 1000 members of the local Nepali population, with the integral help and involvement of a specially developed Nepali research committee, as well as close multidisciplinary working across multiple specialities.

- A comprehensive multidisciplinary team was established with specialist input from expert clinicians with special interest and proven record in community testing interventions, academics, local PHE representatives, hospital community liaison teams, research and governance teams and local council representatives.
- This research team was completed with the help of a newly (specifically) developed Nepali research committee, with the inclusion of a nominated member of the Nepali community

acting as a formal appointed member of the Research team, with formal accreditation and status.

- 5 community venues were chosen for their established familiarity and ease of access to known Nepali population clusters, with testing delivered by DBS testing kits between March 2013 to January 2015 over 17 individual sessions.
- 984 individuals took part in testing, of whom 54% were female, and with a median age of 66 years.
- The median residence period in the UK was 36 months, with 85% of the Nepali community resident for < 5 years, and close 20% who had arrived in the past year.
- Advertising for testing activity was limited and modified in the face of far-right groups and anti-migrant sentiments expressed in the local community, and given the fears of our Nepali research committee.
- Word-of-mouth was the principal route to disseminate interest and attendance at testing sessions, with radio advertising on national Nepali military service networks that is likely to be a powerful tool that can be utilised in further, or future health promotion initiatives.
- Engagement with members of the research team was positive during study presentations delivered to Nepali groups, and in interactions during organised testing sessions.
- The median number of individuals per household in tested community was 2.
- The median number of years of schooling by all participants was 0, with a transition that is evident in participants above 40 years, and with lower levels of schooling in older female participants as well. Literacy in English was low in older participants, with a degree of functional illiteracy towards Nepalese seen in elderly participants as well.
- The prevalence of active HBV and HCV was low in the 984 unique individuals tested. 3 individuals had evidence of HBsAg positivity (0.3%), and 4 individuals had detected HCV Ab, but with RNA that was then undetectable on subsequent DBS sample testing in all 4 of these individuals.
- HBcAb positivity was high, with HBcAb identified in 91 individuals (9.25%).
- *Potential risk factors:* Over 70% of the population had received vaccines abroad, with a 1/3rd with a history of surgery abroad, and over 90% who had a history of piercings abroad, with the majority of these piercings as infants. Alcohol intake above recommended levels was suggested in 17%, with 34% of these individuals being female. None of these factors demonstrated correlation to HBcAb status in subsequent analysis.
- Multiple logistic regression analysis identified male gender (OR 2.6, p=0.016) and years spent at school (OR 0.88, p=0.025) as possible associations towards HBcAb positivity.

- Variation in HBcAb status was also seen according to district of origin, with a correlation suggested towards those originating from the Myagdi district, but without reaching statistical significance, and data drop out that is likely to be significant in overall analysis.

Implications of findings:

Political, Social and Health impact on CVH testing in migrant communities: Politically in the UK, as with much of Europe, there is an overwhelming desire to reduce migration, with anti-migrant sentiment that appears on the rise in many political parties across Europe, and in mainstream UK politics [Telegraph April 2017, Guardian June 2016, BBC October 2017]. BBVs such as HIV have been used in negative public debates about migrant communities by mainstream right-wing groups such as UKIP [Telegraph April 2015], and the political will and ability to address disease risks in migrant groups, particularly other BBVs such as CVH would seem limited in the current political climate. The comments of local political leaders in Aldershot are likely to inflame and drive anti-migrant sentiment that already exists in the community, and importantly are likely to adversely affect the Nepali community's integration, and perception of belonging.

The anti-migrant sentiment that arose during our testing study is evidence of the pressures that the Nepali community is facing at the society level, and council members involved in our research group expressed significant concerns informally about the risks of inflaming tensions in the local community in trying in to understand CVH disease risks in the community.

These political and social factors would be expected to negatively impact on the social determinants of health, effecting social and community networks, as well the agency of individuals, with negative expectations on healthcare engagement in CVH, and other health conditions [Dahlgren and Whitehall 1992]. In addition, the findings from our testing study demonstrate low levels of education and literacy in the vast majority of participants, which is likely to further impact conventional health engagement strategies, and suggests a greater need for resources to support and build health engagement strategies in CVH and beyond.

CVH testing policy: The historic context of CVH policy in the UK suggests there are established deficits in awareness and understanding of CVH, as well as gaps in the integration and coordination between specialist and primary and community (e.g. Drug and Alcohol services). NICE CVH testing policy provides a comprehensive list of groups who should be approached for testing, and primary care services would be principal agent to deliver these initiatives, given the existing provision and access opportunities, as well as the high levels of trust the service holds with the community, and of course the potential access for migrant groups at the national level. Whilst policy recommendations have

many uncertainties, there is internal consensus in the policy development group on the need to better understand CVH risks, and to reduce the rising morbidity and mortality risks seen with liver disease and CVH.

However, the Political Prioritisation Framework demonstrates gaps that exist in policy reaching the agenda setting process, and how policy can be achieved; with a lack of leadership and oversight that is most evident, as well as a gap between the macro level policy development stakeholders, and the meso and micro-levels where policy is coordinated and actioned. Policy actions (recommendations) demonstrate a lack of authority, with the need for clear practical recommendations for community practitioners to follow, and greater detail and simplicity in actions and referral pathways for community practitioners to follow. The lack of resources identified or allocated towards policy is also a significant weakness, and the provision of simple practical forms, or procedures for GPs to follow would go some way to alleviate the resource hurdles that disparate GP practices face.

NICE CVH testing policy development started before the introduction of the Health and Social Care Act, with a significantly negative impact that policy is likely to have suffered as result, most notably with its contribution to the loss of the National Liver Strategy, and the central oversight that one presumes would otherwise have helped coordinate testing activity. Testing policy was also not able to predict the paradigm shift brought on with the development of DAA based therapies, and the current commissioning role of NHSE, which would significant (positive) impact on the cost-effectiveness of CVH testing interventions, and take away CVH treatment commissioning needs from primary care and CCGs; both which would be presumed to work favourably towards improved testing efficacy and uptake.

Qualitative studies between Primary care and the Nepali community: Participants in the Nepali focus groups demonstrated a high level of awareness towards liver disease, and although disease is principally identified as jaundice, it is also seen as a serious condition, with fear that is expressed through personal reflections of mortality in close relatives.

Considerable uncertainty exists in how to explain liver disease, or its causes, and particularly how to protect from illness, with a keenness to engage and understand more about disease from health professionals.

Multiple potential causes and treatments of disease are discussed, with a plurality between internal and external causes of disease; including spiritual causes as well as food and water pollutants. Negative perceptions and stigma are expressed, most notably in younger female participants who have not had any first hand contact with liver disease patients/relatives. However, overall, despite the predominant negative perceptions to cooking practices or food hygiene, there is an expressed desire

to support members of the community who may be effected by CVH, and a recognition by all that liver disease is something that can affect anyone.

Low levels of literacy to English, and a functional illiteracy in Nepalese is again demonstrated, with considerations that need to be borne into the development of health education and intervention initiatives.

Looking at the focus group findings between the local Nepali community and the GPs who serve them, there is a keen expression in Nepali focus groups to learn more about liver disease and to engage with health professionals and GPs in particular. However, looking at our qualitative study in local primary care it is apparent that testing is viewed not only as a low priority, but as a subject that is largely avoided with the perception that migrants would not be aware of liver disease, or want to engage in discussions regarding this.

Indeed, concerns of prejudice are strongly expressed in GPs, and whilst stigma is identified in Nepali discussions, there is no suggestion overall of negative perceptions to testing, and an overwhelming desire to gain better self-control and understanding of disease risks, which remains supportive of community based testing offers.

Testing activity is however a low priority in primary care, with no expressed awareness of testing policy, or policy recommendations to offer testing to migrant groups. Strong negative views are put forward regarding the merits of CVH testing, with misunderstanding that seems evident in disease awareness, and with the risks that existing chronic CVH patients are under-prioritised for onward referral, coupled with testing activity that remains largely non-existent.

The negative views of testing in primary care are expressed principally by senior members of the team, and whilst others in the group may hold opposing, or more informed views, these are not expressed, and the controlling current testing activity seems to be run by these individuals. Of note, the negative perceptions of offense and racial profiling were not apparent in discussions and presentations to Nepali community groups as part of our study promotion, or during testing activity.

Modifiable factors to improve testing seem principally resource based from focus group discussions, but overarching to this is the need to improve the awareness of CVH, the morbidity and mortality toll that it holds, and the revolutionary cost-effective treatments that can be delivered if disease is identified at the right-time.

At the personal level, the richness of the qualitative data from the Nepali community was illuminating in understanding the importance of awareness and perception in how we design and reach out to migrant populations, and has changed my perspective in how I approach and appreciate the

complexities of patient care. The richness and openness of the primary care data was also illuminating in unexpected ways, identifying perspectives that I had not appreciated, and that create challenges and opportunities to manage going forward.

Community CVH testing study:

Study design: Our multidisciplinary team worked well together under the leadership of the core research team to explore CVH risks in the Nepali community. The Nepali research committee was invaluable in identifying testing locations, and in participant recruitment and in facilitating testing activity. Embedding key Nepali community leaders into the research team through formal links helped provide authority and inclusiveness to our Nepali colleagues, as well as motivation to act as peer-support mentors for testing promotion.

Given the heterogeneous nature of the Nepali population, divide across multiple castes and religions; involvement of the Nepali research committee was crucial in identifying potential testing sites around (otherwise unknown, or conjectured) population clusters, as well as study advertisement.

Advertising: Word of mouth proved a powerful media to recruit participants, presumably building upon strong national ties that exist in the newly arrived community, as well as the underlying socially-minded nature of the community, who are often seen together in groups in the local community, and who attended CVH testing sessions as groups, rather than individuals. Although we were limited in our ability to utilise written leaflets, invites of posters in the general community, it is likely that word of mouth, and spoken or visual medial is the preferred tool to reach out to members of the community to promote health engagement, with corresponding findings that are of course evident from our focus group work, as well as the low levels of formal education identified during the course of our testing study. Indeed, the late addition of radio-advertising (following a formal telephone interview) promotion on national Gurkha breakfast radio seemed to produce a powerful uptake in participant numbers, many who we could not accommodate for testing.

Testing activity and engagement: Informally, the Nepali participants expressed satisfaction with the community testing sites, and we concentrated our testing activity to the busiest and centrally located centre in Aldershot. DBS (dry blood spot) testing was well tolerated, and easy to deliver, with only a few samples that required repeating (due to a small amount of blood on the first finger prick). Whilst research nurses delivered this testing as part of our research study, there would seem no preclusion to this being delivered by non-healthcare trained professionals, provided the correct training facilities

were in place; with a role for these kits also in primary care, and self-testing kits that remain a potential mailed testing route as trialled in HIV testing initiatives [PHE Dec 2016].

Community testing did though require a reasonable staff provision per testing activity (6-9), in addition to the needs for 4-6 members of the Nepali community to help with patient information, consent and testing.

Demographics: The majority of testing participants were elderly (median age of 66 years), and whilst this age distribution is skewed to an older age in comparison to earlier reports from 2008, this may also be a reflection of the older ex-servicemen and their dependents who have since arrived in the UK. These older individuals may also provide a representation of cumulative risks that would have developed with undiagnosed CVH over this period.

All participants were first-generation migrants, with the majority (>85%) who had been in the UK for less than 5 years, supporting the concept of a new migrant community in the local Nepali population. And, whilst there was a wide variation in the district level origin of these individuals, the overall distribution is similar to earlier estimates by CNSUK, in keeping with a select extraction of the Nepali population who are now resident in the UK.

CVH prevalence: The absolute numbers of active infection suggested through our study is very low in the Nepali community, with HBsAg positivity (0.3%) which is on par with those identified in the background UK population (0.3% [PHE 2013]). Whilst 2 of the 4 participants with HCV Ab detected on DBS did not attend subsequent clinic follow-up, all 4 were RNA negative on further DBS sub-testing, and therefore one presumes that no cases of active HCV were detected, with prevalence rates therefore for HCV that are between 0 to 0.41%.

CVH prevalence: The absolute numbers of active CVH infection suggested through our study is very low in the Nepali community, with HBsAg positivity (0.3%) that is on par with those in the background UK population (0.3% [PHE 2013]). Rates for HCV infection seem to be lower; between 0 to 0.4%, with all 4 participants who were RNA negative at subsequent DBS testing, but with 2 patients who did not attend clinic follow-up to confirm HCV RNA negativity.

As such active infection, and immediate risks and needs for treatment and contact tracing activity appear low based on this information.

However, this is contrasted with high levels of (previous) HBV exposure, with 9.25% of the population (91/984) identified as HBcAb positive. Looking at the internal validation data for the DBS testing kits used in this study (table x), the reported specificity is 100% for HBcAb detection, suggesting that this is an accurate representation. Logistic regression analysis identifies male gender and lower education

as possible associated factors with HBcAb exposure, and there does not appear to be an alternate (overt) risk factor identified in our study to account for HBV exposure. Therefore, one would presume a vertical transmission route, or childhood exposure in these individuals, with the corresponding expectation that 80-90% of these infants will develop chronic active HBV, and 30-50% of children if infected before the age of 6 years. As such, the risks of active HBV in other members of the community who may have the same exposure risks seems to remain, with the need for ongoing investigation.

Risk factors for CVH: Male gender and lower levels of education were the only statistically significant risks factors in relation to HBcAb status, with district level origins that suggest some association, but without reaching significance.

Formal education is generally low in the study population, with particular deficit in those over 50 years. Nevertheless, age does not appear as a statistically significant variant in analysis, and educational status may reflect broader socioeconomic relations that positively influence health outcomes as noted in other health settings [Feinstein L 2006].

It is of interest that despite relatively higher rates of exposure to invasive iatrogenic procedures abroad, as well as almost universal piercings at birth in presumably rural areas, rates of infection remain low, and without statistical significance towards HBcAb positivity.

Comparison in Literature:

Policy analysis:

Formal policy level analyses are not apparent for previous CVH testing initiatives, and remain absent in many conventional chronic disease states. The Priority Setting Framework developed by Shiffman and Smith was constructed based on policy applied to low and middle income countries, but with a heterogeneous and inclusive analysis provided in the following review by Walt and Gilson, including its application into HBV vaccination uptake rates [Walt G 2014].

Policy analysis is seen to be both intuitive and complex, with findings that may only become apparent during the analysis process. CVH testing policy is seen to have been developed in a top-down fashion, with a loss of oversight and coordination brought on through the loss of the National Liver Strategy, as well as demonstrating a lack of authority in policy objectives, disparities between the internal and external frames in how policy is viewed, and in the resources that can be utilised to achieve policy objectives.

HIV policy is perhaps a good policy comparator, albeit in the context of disease with far greater reach in terms of its recognition, funding and impact at a societal level, and with strong community actors who are well recognised in the public and internal arena.

Similar to CVH, HIV has received renewed motivation to improve testing and treatment as part of global initiatives to drive up testing, identification and linkage to care to try and control and eliminate disease by 2030 [PHE December 2016]. Updated guidance to increase HIV testing uptake have also been released by NICE in 2016 [NICE December 2016].

At the Actor level, although the same stakeholders and relations underpin HIV testing and onward care, there is a greater role for Local Authorities through sexual health clinics, and the position of actors such as PHE is far stronger. PHE runs dedicated internet awareness raising pages, and promotes testing, even with the provision and funding of home DBS testing kits, with mailed results that are sent to participants [PHE December 2016]. As well as this there is a stronger role for community interaction, and community-based groups to encourage HIV testing, with PHE funded initiatives to identify (and fund) new testing and linkage initiatives. Grassroots support is more vocal and varied, with wide scale public promotional testing adverts distributed across the country; without fear of stigma, issued with celebrity support from leading figures.

The internal and external frames of HIV testing is well defined, and despite falling numbers of cases, there remains a strong impetus to improve testing, with the stated call in policy documents to “normalise testing”, thereby aiming to adapt testing perception and behaviours [PHE December 2016].

HIV policy is of course shaped by the AIDS epidemic, and how this has been portrayed and perceived, and whilst treatments have progressed hugely over the past decade, there has not been a contextual revolution in treatment as seen in HCV over the same period, with a policy window that one could argue for more strongly in HCV and CVH testing drives.

Considering the Issue Characteristics in HIV policy, there is greater clarity in the need for treatment in patients who are identified, with severity measures that are well defined in clinical practice. But there are also similarities with CVH testing, with uncertainties that exist in prevalence rates, and the groups to target.

Considering the Outcome category in the policy prioritisation framework model, the resources allocated HIV testing are similar on some levels, with commissioning that is coordinated between Local Authorities and CCGs in a similar fashion to CVH, but with greater acceptance and standardisation at the Local Authority level due to its commissioning role in Sexual Health services. Technical resources appear in newer HIV policy, with easy to access prevalence assessments for practitioners, which may of course represent technological advances rather than any other variance. Testing recommendations

for HIV do appear more authoritative, with practical testing strategies given to GPs with New Patient testing, Opportunistic testing, although there is flexibility in the decisiveness of some of these recommendations, presumably in relation to the sensitivities perceived of HIV testing offers.

Overall, it can be seen that HIV testing policy has many similarities to CVH care, but with advances that are clearly evident in HIV policy. The Actors involved in testing activity appear more supported from PHE, and likely also from Local Health Authorities, with the involvement of voluntary organisations, who have a stronger community presence, and external frame in view of the greater awareness and recognition of HIV. The public recognition and support for HIV is far higher, with celebrity support for testing, as well as widespread media advertising for testing uptake with the aims to normalise testing.

These testing endeavours and successes are despite the stigma associated with HIV, and suggest that greater coordination and involvement of actors in the testing process, as well as improved public awareness can modify current misperceptions if these exist, and should act to re-assure other providers and actors to support wide-scale CVH testing uptake in keeping with official CVH testing policy.

Focus Group analysis in Migrant groups and Primary Care:

At the community level, Nepali participants expressed high levels of awareness towards liver disease, with jaundice used as the principal reference in discussing and defining disease, in keeping with the findings of previous qualitative studies in migrant groups [Burke N 2011]. Nepali participants do however reference liver disease more strongly than that noted in most other qualitative studies, with first-hand accounts of disease given by all groups, except in younger female participants.

Spiritual causes of disease, and the role of Witch Doctors as external agents responsible for disease and cure are mentioned in all four focus groups, with a role for Spirits mentioned in some other community studies in the US Cambodian community [Uehara ES 2001], and in elderly Turkish participants [Van der Veen YJ 2009], but without strong mention of this association in other migrant studies. It should be noted though, that the perceived role of Spirits and Witch doctors in the current focus groups seems low across the focus group studies, and is principally mentioned on specific exploration by the moderator. In addition, there is no mention of any particular religious paradigms associated with disease, or cure, which may reflect the religious heterogeneity of the Nepali population.

Whilst food and water pollutants are strongly expressed as potential causes of disease, there is also wide range of aetiologies, including viral hepatitis that are mentioned. The understanding of these medical terms is though unclear, and it may be that these terms are understood differently, and in

“linear” learned forms of hepatitis A, B and C, as identified by n other qualitative studies [Burke N 2011].

Stigma is a feature in focus group studies, but without a clear negative effect on testing likelihood, with corresponding studies among community healthcare providers suggesting a lack of disease awareness as a more potent factor to impact testing uptake [Seedat F 2014]. Alcohol is well recognised in focus group discussions in the Nepali community, and it is described principally as a risk in those perhaps back in Nepal, and has negative implications. However, it is often referenced as a co-factor, and it is not expressed as often, or strongly as water and food pollutants as a driver of liver disease. Additionally, it may be that liver disease and CVH is viewed in a different fashion for those Nepali participants now resident in the UK compared to those in Nepal, as suggested by Drazic et al. in qualitative studies into the South Asian community in Australia [Drazic NY 2013].

Overall, the Nepali community seem supportive and keen to engage with health teams to learn more about liver disease, with engagement that seems more positive than that identified in other community studies.

At the primary care level, the low levels of awareness in CVH testing seems in keeping with previous findings following the 2004 HCV Action Plan [D’Souza RF 2004], and the findings of more recent studies, with the majority of at-risk individuals that remain untested for CVH in UK primary care [Datta S 2014].

There is a lack of awareness towards CVH testing policy expressed during the focus group, and whilst there may be some (tacit) underlying knowledge of testing needs in migrant populations (as suggested by military affiliated GPs); the lack of any expressed policy-knowledge makes it difficult to associate concepts of a second translation gap, or to associate the lack of testing activity as a true measure of clinical or diagnostic inertia. It is the case though, that many of the aspects of a Clinical/Diagnostic Inertia are otherwise present; with “soft” reasons provided not to proceed, an overestimation of current levels of testing, and a lack of education and training that is likely to be evident [Phillips LS 2001, Salisbury C 2006].

Gaps in CVH knowledge, as suggested in the classification and importance afforded to chronic CVH are well documented in primary care [Bechini A 2012], as are gaps in knowledge relating to serology results, and in the long term risks of CVH, including HCC [Guirgis M 2012], with common findings therefore to the current focus group study.

The negative opinions taken towards CVH testing in migrant groups is though more strongly expressed than in prior studies in primary care. Indeed, whilst practitioners express discomfort in approaching testing due to potentially awkward discussions on risk-activity, there is no specific mention of race, or

fears of prejudice/racism as a barrier to testing activity [Jewett A 2015]. Similarly, the concerns of “causing harm” as reflected in our current focus group is not reflected in earlier studies, with the raised concerns on insurance, and the “harm to loved ones” not mentioned in prior qualitative studies in primary care.

The findings from our current focus group study therefore paint the picture of a more negative attitude towards CVH testing and a lower priority to CVH testing in migrant groups. This may be a reflection of primary care views outside of the major city centres, with most research studies affiliated to urban centres. But it remains reflective of the real-life views of GPs who would traditionally have managed a more homogenous population, but are now faced with the arrival of a new migrant community, with focus group data that suggests an ongoing mismatch in perception, and gaps in knowledge relating to CVH, as well as an absence of, and lack of priority afforded to testing activity.

Community CVH testing strategy:

The Nepali community is a heterogeneous population with regard to religion and caste, with difficulties in accessing and promoting testing through a single source, such as religious settings or faith leaders, as have been successfully utilised in other research studies [Uddin G 2010, Lewis H 2011, Zuure 2013].

Despite this, we were able to develop a successful CVH community testing study to test close to a 1000 members of the local Nepali community over 17 testing sessions, with recruitment (testing) numbers that appear in the medium range in comparison to other large scale testing interventions (table x) with the largest, and highest profile BFreeNYC project achieving CVH testing in close to 9000, mostly Chinese origin American individuals over a 4-year period; with an estimated 700,000 ethnic Chinese individuals resident in NYC [Pollock H 2011, Wikipedia NYC].

We were restricted our advertising strategies for participant recruitment, with word-of-mouth the predominant route for recruitment. Most community testing endeavours utilise a range of strategies, with national media, and internet based advertising used widely in studies in migrant communities, without significant stigma that was reported as a result [Pollock H 2011, Richter 2014]. Word of mouth though is supported as a recruitment tool in most community studies, although its effect is difficult to qualify among the multiple strategies often employed.

Nepali community volunteers formed an integral part of testing activity, and played a formal role in directing testing activity and locations through the dedicated Nepali research committee. Community support is well-established in testing, providing grassroots support and access to community networks and language support. In the review by Robotin and George the “ideal” community-based intervention

is suggested to be a “true partnership” between technical experts and these community advocates, providing support in a socio-cultural context to promote and develop testing ideals [Robotin M 2014].

We sought to enhance this position with our Nepali community volunteers, through formal recognition and inclusion into the research team for select community leaders. The success of the study was due in large part to the active participation and peer-support given by a large number of community volunteers. Members of the community were very keen to help and engage in health interventions, and it may be that this volunteer action relates to the broader acumen in health engagement and volunteering seen through the female community health volunteers in Nepal, who are widely credited with having brought down rates of maternal mortality [Panday S 2017].

The absolute numbers of active CVH detected in the tested Nepali community is very low, with rates comparable to or lower to that seen in the UK population, but with higher rates of previous HBV exposure that is suggested. These findings do correspond to prevalence rates suggested from the limited studies available in Nepal, with HCV Ab rates of 0.6% detected in healthy volunteer studies in 1998, and with similar prevalence rates (0.66%) in blood donor testing in 2008 [Shrestha SM 1998, Shrestha A 2016]. For HBV, testing data in healthy volunteers from the early 1990s suggest HBsAg prevalence rates of 0.9%, with high levels of HBcAb positivity detected at close to 44% [Shrestha SM 1990]. More recent publications on Nepali viral hepatitis risks mention the same prevalence for HBV at 0.9%, but use data from the early 1990s to evidence this [Shrestha A 2015, Shrestha A 2016]. Antenatal studies in Nepal from 2012 have also shown low level of detected HBsAg (0.5%), and higher rates of HBcAb positivity (28.5%) that are again seen. Ethnic and likely geographical variation is also suggested in the same 2012 review, with HBsAg prevalence rates of 6.6% noted in participants from the Surkhet valley in a dedicated testing study in Nepal; but with low levels of representation from individuals in the Sukhet valley in our testing study [Shrestha SM 2012].

As such, the low levels of HBsAg positivity detected in our current study seem comparable to the data from previous research-based studies in Nepal, but with the primary data set for HBV that is from an individual study in 1990. Higher rates of HBcAb exposure seem reported across several studies, and whilst the reasons for this are not clear, low levels of documented infection in those under 5 years, and amongst tested pregnant women have led to suggestions that self-limited infection in older children may be a possible reason for this trend; but with no formal assessment of this finding, or any possible implications [Shrestha SM 2012].

The CVH risks identified in our testing study of the Nepali population fall below the 2% prevalence rates suggested as the threshold for case-finding in testing policy [NICE 2012], particularly in HCV, highlighting the heterogeneity that exists in migrant communities. However, given the significant

HBcAb risks identified in the tested population, and the nature of the elderly self-selected population selected for testing, it becomes difficult to ignore these risks in the onward support for CVH testing in this community.

Limitations:

Focus group studies in the Nepali community were conducted in Nepalese, and whilst this preserves the richness of language and expressions during focus groups, it did require individual session translation by a single Nepali volunteer (overseen by R Tiwari), with data losses that would occur in this process. Whilst future qualitative studies in the Nepali community are likely to require similar Nepalese mediated sessions, one could endeavour to have greater effort through synchronous or collaborative translation of extracts.

There were significant data losses in the first part of our CVH testing study towards the place of origin of over 300 participants. This would have impacted the outcome and any possible statistical association that may exist between geographic origin and HBcAb risks. The population demographics of our testing study identified an older Nepali population, and whilst this may be representative of many in the newly arrived community, our sessions were limited to weekday daytime sessions; driven principally by the needs and availability of our (large) research team of nurses and community volunteers. Whilst targeted recruitment to younger Nepali individuals at college campuses, and work settings were considered, these were all felt to offer too high a risk of stigmatisation to our participants and were not explored.

The effects and limitations of anti-migrant sentiment in the local community is also likely to have effected recruitment, and one presumes that posters or leaflets in health settings, and communal access points would have improved community awareness and uptake.

The purposive nature of recruitment to our focus groups, and the nature of community based testing interventions is likely to produce a self-selection bias, and may therefore miss those participants who choose not to engage with these measures, but who may be at greater CVH risk due to other underlying factors [Uddin G 2010]. And whilst other testing strategies such as “opportunistic” CVH testing in primary care may provide an alternative route to reach these individuals, our primary care work suggests that current CVH testing in migrant communities in an opportunistic manner is not feasible.

Finally, in the original design of this thesis, I had hoped to undertake a whole-system approach to provide an analysis of the gaps that exist in testing across the macro, meso and micro levels of the health system. However, the current policy does not formally examine current meso-level actors such as CCGs or Local Authorities, nor patient advocacy groups; and this relates to the time pressures of

arranging these formal semi-structured interviews. At the same time though, my own presentations to local CCG representatives as part of my study recruitment in primary care, as well as in local Clinical Reference Groups (CRGs) all suggested low levels of awareness of CVH testing guidance in its current form, and it is likely that CVH testing would have been identified as a low priority; in keeping with the findings of other studies in Local Authorities [HCV Action 2014]. Boundary spanning activities that I conducted working with the British Liver Trust as part of the “Love Your Liver” campaign during the time of this thesis, did highlight strong levels of engagement with groups that we would not usually meet to discuss and explore liver disease; providing (confidential) outreach drop-in visits in community settings, including work settings (Appendix).

Further research:

Looking again at the overview of commissioning responsibilities and the principal actors involved in CVH testing (figure 37), there are multiple agents and complex relations that are integral in the optimal provision of CVH case-finding activity.

The current study has focused on the macro, policy-level actions on CVH testing, with principal focus in primary care, as well as micro-level work with local primary care physicians and members of the local Nepali community.

A more comprehensive approach would be to involve multiple levels across this system, adopting a whole-system approach, looking at the complex relations that often govern outcomes in healthcare across these levels, which may achieve a relative positive or negative impact on testing activity [Litaker 2006]. A system-wide approach across macro, meso and micro levels, may also help in identifying principal leverage points for action that may otherwise be missed [Dattee 2010, Chysanthaki 2013].

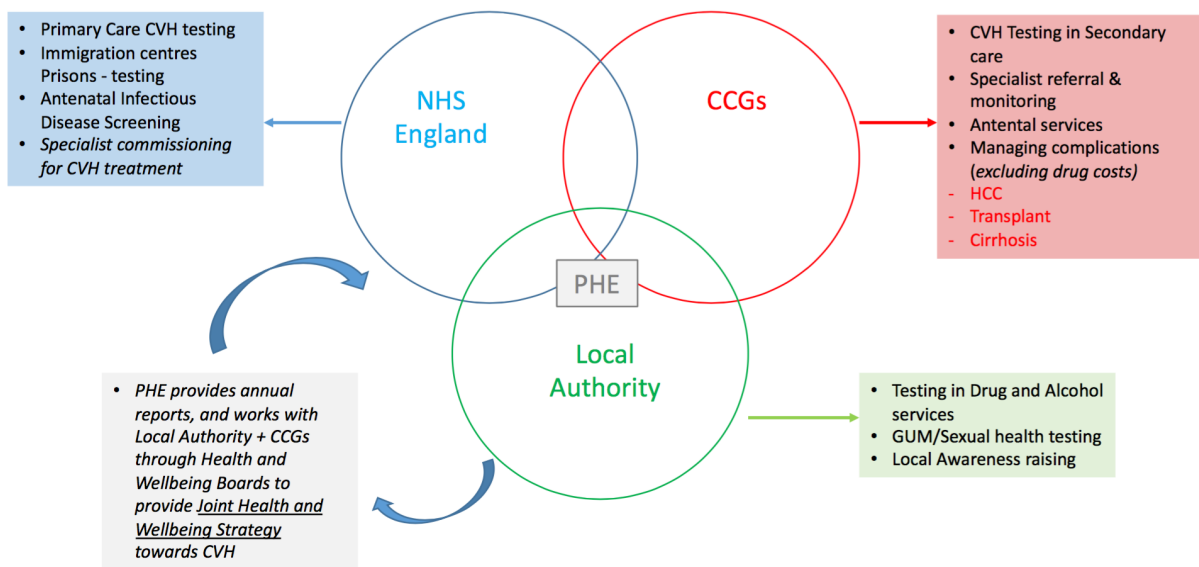


Figure 37 Overview of commissioning responsibilities in CVH (Chronic Viral Hepatitis) testing; (PHE = Public Health England, CCG = Clinical Commissioning Group/Local Health Provider, HCC = hepatocellular carcinoma, GUM = Genitourinary medicine)

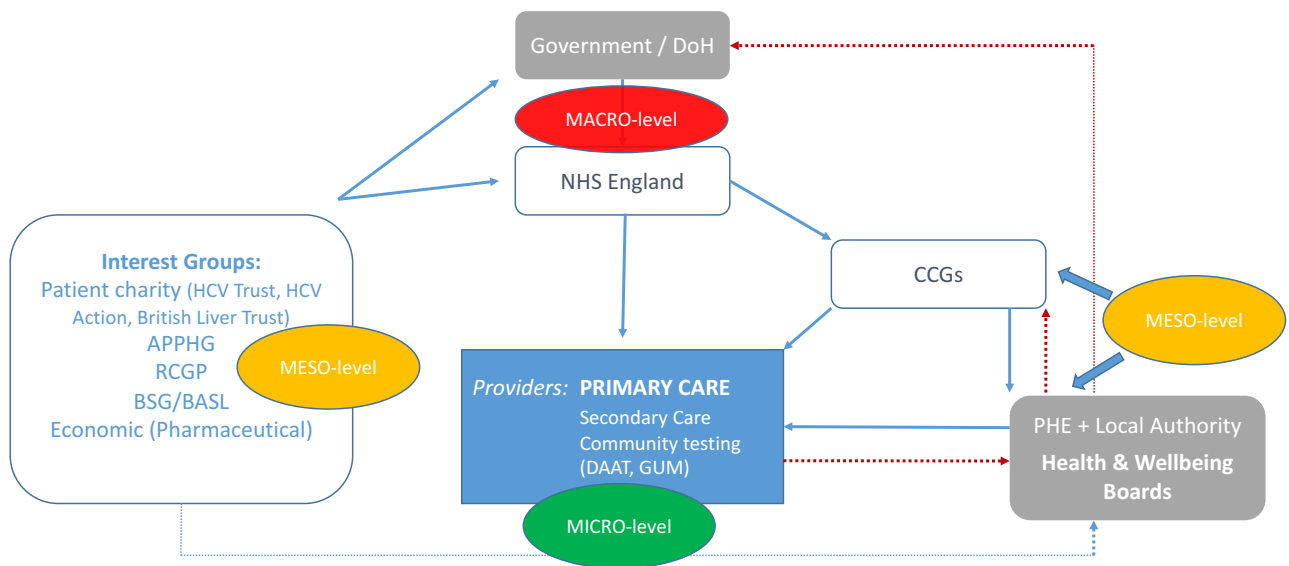


Figure 38: An overview of the complex relations and agents involved in CVH testing activity across Macro (red), Meso (orange) and Micro (green) levels.

Further work at the patient level, also needs to look at how CVH testing uptake can be improved, adopting strategies used in other BBVs; namely HIV. HIV testing adverts are widespread in public spaces without reports of significant stigmatisation. HIV testing enjoys high-profile support, with even Prince Harry taking part in live HIV testing through social media [Independent July 2016] with the support of the Terence Higgins Trust. Whilst the history and context of HIV is different, it will be

important to look at how similar public campaigns outside of specific at-risk groups can be employed in CVH, as this would facilitate greater priority for CVH testing with community practitioners, but also importantly should promote and support agency in at-risk groups coming forward for testing.

At the primary care (micro) level, one of the findings from our focus group study is the absence of any structured activity to identify and offer testing to patients. Whilst some practitioners seem aware of new-patient testing opportunities, there is no established action to support this, and resource difficulties that may exist if this activity is to be widely employed. Another strategy is to identify at-risk groups according to electronic coding data, with the development of MIQUEST (Morbidity Information Query and Export Syntax) codes that I have undertaken and utilised as part of a separate CRN (Clinical Research Network) registered study (CRN 17297), looking at testing invites through mailed invites, opportunistic testing and new-patient registrations. A summary of these codes is presented in the appendix, with the need to explore methods to identify at-risk groups in primary care, and methods to offer testing in the context of primary care services which are overstretched.

Conclusion:

We developed a successful engagement strategy to assess chronic viral hepatitis (CVH) risks in the newly arrived Nepali community, with a comprehensive study of the barriers that exist towards CVH testing across the health system.

The findings of this study suggest low levels of active Hepatitis B and C (HBV and HCV) in the local Nepali community, but with high levels of previous HBV exposure that require further investigation and testing; and demonstrates a heterogeneous risk profile in migrant groups.

Migrant groups, including the newly arrived Nepali community face significant challenges from political and social determinants that may negatively impact health access and engagement, with active anti-migrant sentiments expressed during our study. Broad testing recommendations exist in migrant groups through NICE guidance, but there are gaps in the decisiveness and leadership of policy delivery, as well as the resources allocated to implementation; with the need for improved oversight and coordination.

In primary care, there is a lack of awareness and priority afforded to CVH testing, and a reluctance to engage with migrant communities in testing activity; but with high levels of awareness of liver disease in the local Nepali community, and a desire to engage with health professionals, particularly GPs in health awareness and testing activity; evidenced by the high levels of engagement demonstrated in our community-based interventions.

As such there are barriers that exist in CVH testing at the macro (policy) level, and at the micro level with the delivery of CVH testing to migrant groups in primary care. These factors are likely to impact the access and provision of CVH testing to migrant groups, with additional challenges to health engagement in migrant communities given the rising political and social pressures seen nationally and internationally.

Multidisciplinary interventions over macro, meso and micro levels are required to improve CVH testing provision, with interventions to provide leadership and coordination between CCGs, Local Authorities and NHS England that should facilitate greater adoption and integration of testing in primary care. Agents, such as the Operational Delivery Networks (ODNs) may be able to provide such coordination, with resource and educational support to guide and drive community testing practice. The involvement of patient advocacy groups will be crucial to improve public awareness, with the aim of normalising and supporting public-testing activity.

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Appendix

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Ethics Approvals

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- Nepali Focus Group and Testing Study
- GP Focus Group study

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Additional Research Activity / Future Studies:

Micro level activity – Local Primary Care CVH testing activity

Boundary Spanning Activity – working with the British Liver Trust

Primary care case-finding – developing electronic coding strategies to identify at-risk groups – CAG approval

Primary care case-finding – developing electronic coding strategies to identify at-risk groups – MIQUEST Coding (tested in regional GP practices in KSS)

PRESENTATIONS (National & International):

Nepali Focus Group study – BSG POSTER 2014 PRESENTATION JUNE 2014 (Manchester UK)

AASLD/EASL HCV conference presentation – New York 2014

EASL, ILC 2015, Vienna, Austria – Focus Group Comparator between the newly arrived Nepali community and Primary care Physicians who serve the.

Digestive Disorders Federation (DDF), June 2015: Household contact-tracing for Hepatitis B, London, UK; published in Gut: PWE-118, Volume 64, Issue Supplement 1

Nepali Focus Group and Intervention study – Ethics approval:

Ethics approval for focus group studies in the Nepali community, and the development of a testing intervention were developed and submitted together.


Health Research Authority
NRES Committee South East Coast - Brighton and Sussex
Health Research Authority
Ground Floor, Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 797 22565
Facsimile: 020 797 22592

23 November 2012

Dr Aftab Ala
Consultant Gastroenterologist and Hepatologist
Frimley Park Hospital NHS Foundation Trust
Portsmouth Road
Surrey
GU167UJ

Dear Dr Ala

Study title: Nepali community: Viral hepatitis prevalence,
knowledge, prevention and care pathways
REC reference: 12/LO/1530
Protocol number: 1.0

Thank you for your letter of 19 November 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Nepali Focus Group & Testing study: ETHICS APPROVAL

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Condition specified:

In the section "What are the possible disadvantages of taking part?"- include the following paragraphs:

"Taking part in interviews may bring up sensitive issues about liver disease. It is possible you may be upset about some of the themes discussed if you have or know someone who has liver disease. Please let us know if you need any further information or support.

The interviews take up to an hour in length and you might need to travel to the venue. We will be able to offer you refund of travel expenses if you present your bus ticket."

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV		28 August 2012
Other: Letter to GP		28 August 2012
Other: Letter from funder		21 May 2012
Other: Letter from British Liver Trust		28 March 2012
Other: Poster in English	3	23 October 2012
Other: Poster in local dialect	3	23 October 2012
Other: Participant information form	3	23 October 2012
Other: Recruitment mail for focus groups	2	23 October 2012
Other: Consent form - focus group - Nepalese	2	

Nepali Focus Group & Testing study: ETHICS APPROVAL

Other: Interview schedule in Nepalese	2	
Other: Focus Group Participant information form	4	19 November 2012
Other: Interview Schedule - focus group	3	19 November 2012
Participant Consent Form: for screening - English	3	23 October 2012
Participant Consent Form: for screening in local dialect	3	23 October 2012
Participant Consent Form: Focus group	3	12 November 2012
Participant Information Sheet: Focus group	3	19 November 2012
Participant Information Sheet: Screening	4	12 November 2012
Protocol - tracked and clean	2	23 October 2012
REC application	114296/363320/1/281	28 August 2012
Response to Request for Further Information		24 October 2012
Response to Request for Further Information		19 November 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

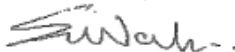
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/LO/1530	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely



Dr Simon Walton

Nepali Focus Group Consent Form

Nepali Community: Viral Hepatitis Prevalence, Knowledge, Prevention & Care Pathways
Chief Investigator: Dr Aftab Ala, PhD, FRCP

FOCUS GROUP PARTICIPANT CONSENT FORM

Please complete the whole of this sheet after reading the information sheet	Initial	Please circle one
1. I have read and understood this information sheet (Version 3, 19-11-12). Please keep a copy for your reference		YES/NO
2. I have had an opportunity to discuss the aims of this focus group and ask any questions		YES/NO
3. I have had satisfactory answers to all of my questions		YES/NO
4. I have received enough information about this focus group		YES/NO
5. I understand that this focus group will be audio-recorded		YES/NO
6. I understand that details of my participation up to the time of withdrawal will be stored anonymously on file and may be used in the final analysis of data		YES/NO
7. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without any of my legal rights being affected.		YES/NO
8. I understand that sections of any of my records may be looked at by responsible individuals from Frimley Park Hospital or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to access my records that are relevant to this research		YES/NO
9. I understand that accurate quotes (without names) from the interviews may be used in the final research publication about this study.		YES/NO
10. I have had sufficient time to come to my decision		YES/NO
11. I agree to participate in this focus group discussion		YES/NO

PARTICIPANT

Signed..... Date.....

Name (BLOCK LETTERS)

I have explained the study to the above participant and they have indicated their willingness to take part.

INVESTIGATOR: Signed..... Date.....

Name (BLOCK LETTERS)

University Ethics Committee

Dr Sanju Mathew
Surrey Business School
FBEL

06 October 2014

Dear Dr Mathew

UEC ref: EC/2014/97/FBEL

Your ref: 14/EE/1159

Study Title: Phase 2: A Feasibility Study of Case-Finding Strategies for the Detection of Hepatitis B and C in Primary Care

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 06 October 2014

The final list of documents reviewed by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper	v.4	20 Aug 2014
Overview of sensitive data access		Sub. 03 Oct 2014
Flowchart: summary of activities		Sub. 03 Oct 2014
NICE 2012 Hepatitis B & C testing guidance	v.1	05 Jun 2014
Curriculum Vitae – Academic Supervisor 1, Professor Aftab Ala		Sub. 03 Oct 2014
Testing invite	v.3	01 Sept 2014
Curriculum Vitae – Academic Supervisor 2, Professor Simon de Lusignan		Sub. 03 Oct 2014
Reply to Norfolk REC team		25 Sept 2014
Draft anonymised post-study questionnaire	v.1	16 Jun 2014
Confidentiality Advisory Group (CAG) Outcome letter		08 Aug 2014
Reply letter to Norfolk REC opinion		24 Sept 2014
Curriculum Vitae – Academic Supervisor 3, Dr Jane Hendy		Sub. 03 Oct 2014
GP display poster		24 Sept 2014
CCG map		Sub. 03 Oct 2014
Consent Form	v.4	01 Sept 2014
Participant Information Sheet	v.5	08 Jul 2014
Protocol	v.10	01 Jul 2014
Summary CV for Chief Investigator		29 May 2014
Full CV for Chief Investigator		Sub. 03 Oct 2014

This opinion is given on the understanding that you will comply with the University's Ethical Principles & Procedures for Teaching and Research.

If the project includes distribution of a survey or questionnaire to members of the University community, researchers are asked to include a statement advising that the project has been reviewed by the University's Ethics Committee.

If you wish to make any amendments to your protocol please address your request to the Secretary of the Ethics Committee and attach any revised documentation.

The Committee will need to be notified of adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons. Please be advised that the Ethics Committee is able to audit research to ensure that researchers are abiding by the University requirements and guidelines.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

pp 

Dr Sophie Wehrens
Research Integrity and Governance Officer, Research & Enterprise Support

PHASE ONE: Focus Group sessions amongst Primary Care Physicians to explore the factors that facilitate and inhibit hepatitis B and C case-finding practice

Chief Investigator: Dr S Mathew (Prof S de Lusignan – Supervisor)

Focus Group Invitation:

Dear Colleague

We would like to invite you to take part in one of our focus group studies. Before you decide we would like you to understand why this research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish and ask us if there is anything that is not clear.

This work is being conducted as part of a PhD programme looking at the problems that exist in translating viral hepatitis testing guidelines to clinical practice.

Purpose and background

Hepatitis B and C (HBV and HCV) disproportionately affect at-risk groups in the UK. National and international guidance recommend testing in at-risk groups, with recent NICE testing guidance issued in 2012. However the majority of patients lie undetected in the community and previous studies have highlighted gaps in the knowledge and practice of community case-finding in primary care. Knowledge relating to viral hepatitis and its management has been historically poor and patchy across many different groups in the health service.

Little is known about the perception of General Practitioners towards case-finding practice, and as to what factors facilitate or hinder testing practice in the community. As the majority of at-risk groups will be present to primary care services, the perception of GPs towards case-finding and viral hepatitis is important in developing new strategies to optimise HBV and HCV testing.

Aims and objectives of the study:

The primary aim of this study is to investigate the understanding and perception of GPs & Practice nurses to viral hepatitis case-finding, with secondary aims to assess practitioners' knowledge and experience of case-finding and the recent NICE hepatitis B and C testing guidance.

What does taking part involve?

We will ask GPs or Practice Nurses to take part in focus-group sessions to explore the understanding and perception of case-finding practice, as well as HBV and HCV in general. These sessions will be led by a moderator (a clinical researcher with a special interest in hepatology), and will last between 30

PHASE ONE: Focus Group sessions amongst Primary Care Physicians to explore the factors that facilitate and inhibit hepatitis B and C case-finding practice

Chief Investigator: Dr S Mathew (Prof S de Lusignan – Supervisor)

to 60 minutes on average. Individual or groups of GPs will be involved in these sessions, and all sessions will be conducted by a skilled moderator with the agreement that all views expressed will be treated with confidence within the group.

Focus groups will be audio-recorded for transcription after the event by the moderator, which will be undertaken at the University of Surrey. All personal-identifiable and patient-identifiable details will be removed and audio recordings deleted after transcription to maintain anonymity.

What will happen to the results of this study?

All responses will be treated confidentially and anonymised. Focus group data will be analysed to identify key themes relating to HBV and HCV case-finding practice. The research may be published in the form of academic papers in healthcare, and may also be presented at meetings. These results will also be used to help develop further research interventions to improve community case-finding practice.

How to withdraw from the study:

You are free to withdraw from the study at any point without giving a reason. Please use the contact details below to inform us. We can remove data up to 2 weeks after a participant takes part in the study, after which anonymous transcription will lead to some data being included in data analysis.

Who is organising and funding this study:

This study has been organised by the University of Surrey, and will form research as part of a post-graduate degree from the faculty of Healthcare Management and Policy.

It is supported by a grant from the National Gilead Fellowship award.

Payment and expenses:

We are not able to offer any payment or expenses cover for these sessions, but would aim to hold these sessions in a location that is local and convenient to you, typically in one of the practice rooms.



PHASE ONE: Focus Group sessions amongst Primary Care Physicians to explore the factors that facilitate and inhibit hepatitis B and C case-finding practice

Chief Investigator: Dr S Mathew (Prof S de Lusignan – Supervisor)

Who has reviewed this study?

This study has been reviewed by the development team at the University of Surrey.

For further information please contact:

Dr Sanju Mathew
Faculty of Health Care Management and Policy
University of Surrey
Guildford, Surrey GU2 7XH s.mathew@surrey.ac.uk

If you decide you would like to take part then please read and sign the consent form.

Thank you for taking the time to read this information sheet and to consider this study.

**NEPALI COMMUNITY: VIRAL HEPATITIS PREVALENCE,
KNOWLEDGE, PREVENTION & CARE PATHWAYS**

Participants Information Sheet

An invitation to you to participate in a research project

We are asking if you would like to take part in a medical research project which we think will be important to the entire Nepalese community in this country. We hope this sheet tells you what you want to know about our project. The sheet tells you what will happen if you take part and what the risks might be of taking part.

Whether or not you do take part in this project is entirely your choice, you do not have to take part for any reason.

We need to know that you understand what will happen before we take a sample of your blood. Please ask any questions you want to about the project and we will try our best to answer them.

1. Nature and purpose of the project

We are trying to find out whether people who were born in Nepal are infected with certain viruses that can cause liver disease. We know that viruses that can cause liver disease and hepatitis ('jaundice') this is unusual in people born in the UK, but we think that people born elsewhere may be at greater risk of infection. We believe that people born in Nepal may be at greater risk and we want to find out if this is the case. (A scientist would call this the prevalence of the virus).

Chronic Viral Hepatitis – what is it and what does it do?

A form of liver disease (chronic viral hepatitis) is commonly caused by two viruses – hepatitis B and hepatitis C. Both of the viruses travel in blood and can be passed on by contact with another person's blood or body fluids. Both viruses can be passed on by the following methods: non-sterile medical equipment, blood transfusion, body piercing such as ear piercing, tattoos, sharing tooth brushes, acupuncture, dirty used razors, recreational drug use, different sexual partners, mothers to their baby. Liver disease like this (chronic viral hepatitis) does not always cause major problems; but sometimes may need treatment and regular clinic checks. We have drugs that we can use to treat this kind of liver disease and these drugs work for most infected patients. Unfortunately, this kind of liver disease (chronic viral hepatitis) can be a silent disease for a number of years and people who are infected often don't realise that they are infected until serious liver damage has occurred.

2. How many people who carry the virus go on to develop liver disease (chronic viral hepatitis)?

- Of those people who test positive to Hepatitis C (HCV) around 75% will go on to develop liver disease (chronic viral hepatitis).
- Of those people who test positive to Hepatitis B (HBV) around 40% will go on to develop liver disease (chronic viral hepatitis).

3. What is the treatment for those with this kind of liver disease?

- Treatment of Hepatitis B (HBV) is with antiviral drugs which are usually continued for many years and successfully suppresses virus in the vast majority of patients.
- Treatment of Hepatitis C (HCV) is with antiviral medicines that are designed to stop the virus from multiplying inside the body and prevent liver damage. It usually continues for 6 months up to one year and is successful in more than 66% of all patients.

4. Project Design

This research project is designed to find out how many patients from Nepal are suffering from viral hepatitis – a type of liver disease.

5. Project Medications

This project does not include trying out any new drugs (medicine). Anyone found to need medicine will be given drugs we already use.

6. Project Procedures

We are most wanting participants who were born or whose family come from Nepal to take part. If you would like to take part one of the research team will:

- Talk to you more about viral hepatitis.
- You will then be asked to give a drop of your blood via a pin prick onto a small card paper that will be used to collect blood.
- This paper will then be sent to a central laboratory for testing.
- After testing the sample will be destroyed and no other tests will be performed on this sample.
- **Everyone** who has had blood taken will be invited to re-attend one week later when you will be told the results. Your family doctor (general practitioner) will also be informed of any positive results.
- **If you do not have viral hepatitis:** no further action is needed. At the time of you attending to receive your result we will explain the importance of maintaining a healthy liver and avoiding future infection with viral hepatitis.
- We will test only for viral hepatitis – we will not test you for any other diseases and we will not test you for other conditions that can damage the liver.
- **If you do have viral hepatitis:** you will be asked to attend Frimley Park Hospital where one of the doctors will talk to you about further tests that are needed. You may need treatment to protect your liver and the doctor who sees you in the clinic will explain this. You will be treated just like every other patient with viral hepatitis. However if you are taking part in this project we will ask some extra questions about how you may have contracted the disease:
 - details about where you were born and lived in Nepal
 - how you may have caught the virus
 - how long you may have been infected for
 - other illnesses that you have
- If you do not wish to answer additional questions you will be able to say no (decline to answer).

NEPALESE COMMUNITY: VIRAL HEPATITIS PREVALENCE, KNOWLEDGE, PREVENTION AND CARE PATHWAYS

- The severity of your liver disease will be stored on a computer in an anonymous form.
- If further special tests on your liver are needed, such as a liver biopsy (a very small sample of liver taken from your body), the details of this investigation will be stored on a database. A sample of your virus will be sent to the Public Health Laboratory where the type of virus that you are infected with will be determined.

This will not affect your treatment or subsequent medical care.

7. Risks and Discomforts

- **Time commitment** - The project involves 15 minutes of your time to learn about this type of liver disease (viral hepatitis) and have the blood sample taken. Everyone will be invited back a week after having the blood sample taken (at the same place) to receive their results. If the results are positive we will talk with you to let you know what will happen next (more tests and a visit to the hospital). Some people find waiting for the test results can be worrying.
- **Life Insurance** - Life insurance premiums for people diagnosed with hepatitis B or C may not be set at the normal rate, you would need to inform your insurance company when you are making an application if you have a positive result.
- **Settlement in the UK** – the results of this test will not affect your right to live in the UK.

8. Benefits

- We hope that the results of this project will tell us how many people from Nepal have viral hepatitis and the results will allow us to decide how best to identify them.
- Individuals who participate in the project will learn whether or not they have liver disease (viral hepatitis) and if they do then they will be able to get treatment which may be helpful.

9. Confidentiality of Records

If you take part in this project your name and details will not be made known to anyone other than the research personnel. All information which is collected about you will be kept strictly confidential. If you consent to take part in the research the people conducting the project will abide by the Data Protection Act 1998, and the rights you have under this Act.

10. What if there is a problem?

We believe that this project is safe and do not expect you to suffer any harm because of your participation. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay to take the case to court. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this project, the normal National Health Service complaints methods should be available to you and you can obtain advice on this, or any other aspect of the project from :-

Patient Advice and Liaison Service (PALS) Telephone: 01276 526530

Email palsusers@fph-tr.nhs.uk (English speaking)

सहमति पत्र

Frimley Park Hospital



NHS Foundation Trust

नेपाली समुदाय: भाईरल हेपाटाइटिस अभिभावी(प्रचलित)को अवस्था,
जानकारी(ज्ञान), रोकथाम र उपचारको बाटो
जांच-पड़ताल कर्ता : डा.अफताब अला

केन्द्र संख्याक:

अध्ययन संख्याक :

यो जाँच/विचारणमा ग्राहकको परिचय क्रमांक:

कृपया, तलको दाहिने तर्फको प्रत्येक कोष्टमा आफ्नो संक्षिप्त हस्ताक्षर गरी परीक्षणमा सहमती जनाउनुहोस्।

१.	म पुष्टि गर्दछु कि, मैले उपरोक्त अध्ययन सम्बन्धी सूचना (सूचना मिति 12 th Nov 2012 परिमार्जित र अनुवादित रूप (४) चौथो संस्करण) सम्झिने, बुझ्ने, प्रश्न गर्ने र उत्तर पाउने मौका पर्याप्त र सन्तोषजनक रह्यो।	
२.	मैले बुझ्नेको छु कि, मेरो सहभागीता स्वयमसेवकको रूपमा हो। म अध्ययनबाट कुनै पनि समय बिनाकारण मन लागेको बेला अलगिन वा छोड्न स्वतन्त्र छु। यस बाट मेरो चिकित्सकिय हेर्चाह र कानुनी अधिकारमा कुनै असर पर्दैन।	
३.	म राम्रोसँग बुझ्दछु कि, अनुसन्धानको क्रममा गरिएको मेरो स्वास्थ्य सम्बन्धी टिपोट र तथ्याङ्क सम्बन्धित आधिकारीक संस्था वा फिम्ली पार्क अस्पताल, राष्ट्रिय स्वास्थ्य सेवा प्रतिष्ठानका जिम्मेवार ब्यक्तिहरुले मेरो परीक्षण सुसंगत भएसम्म आवश्यक प्रयोग गर्न सक्ने छन। म ती जिम्मेवार ब्यक्तिहरुलाई मेरो अभिलेख माथिको पहुँचमा अनुमति दिन्छु।	
४.	म जान्दछु कि, मेरो ओँलाबाट मसिनो सियोले घोची रक्त नमुना सन्कलन गर्न मलाई अनुबन्धन गरिने छ। म अध्ययनको उदेश्यको लागि पूर्व उल्लेखित रक्त नमुना संग्रहणको लागि दिन मन्जुर छु।	
५.	अध्ययनमा भएको मेरो सङ्लग्नता मेरो स्वास्थ्य केन्द्रलाई जानकारी गराइन्छ भन्ने कुरामा मेरो सहमति छ।	
६.	म उपरोक्त अध्ययनमा सहभागी हुन मन्जुर छु।	

सहभागीको नाम

मिति

हस्ताक्षर

मन्जुरिलेने ब्यक्तिको नाम (यदी

मिति

हस्ताक्षर

जांच-पड़ताल कर्ताभन्दा फरक

भएमा)

जांच-पड़ताल कर्ता

मिति

हस्ताक्षर

एक प्रती सहभागी लाई र मूल प्रतिजांच-पड़ताल कर्ता लाई ।

CONSENT FORM

**NEPALESE COMMUNITY: VIRAL HEPATITIS PREVALENCE, KNOWLEDGE,
PREVENTION AND CARE PATHWAYS**

Investigator: Dr Aftab Ala

Centre Number: Study number:

Patient Identification Number for this trial:

Please initial against each box below to indicate agreement:

1.	I confirm that I have read and understand the information sheet dated 12 th November 2012 (version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntarily and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3.	I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from regulatory authorities or from Frimley Park Hospital NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4.	I understand that I will be asked to give a finger prick blood sample. I agree to give a blood sample for the purposes of that study.	
5.	I agree to my GP being informed of my participation in the study.	
6.	I agree to take part in the above study.	

_____ Name of Patient	_____ Date	_____ Signature
_____ Name of Person taking consent (if different from Investigator)	_____ Date	_____ Signature
_____ Investigator	_____ Date	_____ Signature

1 copy for the Patient, and the original to Investigator

NEPALESE COMMUNITY: VIRAL HEPATITIS PREVALENCE, KNOWLEDGE, PREVENTION AND CARE PATHWAYS
Dr Aftab Ala, Frimley Park Hospital; Version 4 11th March 2013

With District level data included, significant numbers of NAs enter, which may affect model performance.

Table 3: Odds ratios, with District level data removed:

	OR	2.50%	97.50%
(Intercept)	0.1649984	0.0145332	1.6459629
GenderI	2.4349292	0.1247615	15.3487466
GenderM	2.5972712	1.4237929	4.784868
Age	0.9930603	0.96203	1.0272233
Months.in.UK	1.0023737	0.9926432	1.0113265
Adults.in.household	0.9129508	0.7589348	1.0774791
Children	0.8226292	0.524449	1.2181124
Years.spent.in.school	0.8821438	0.7865766	0.9759679
Blood.transfusiony	0.9016691	0.2916659	2.2882823
surgery.abroady	0.953584	0.5422141	1.6360678
Dental.worky	1.1670261	0.6919	1.95999
vaccinationy	0.9629342	0.5359541	1.8043675
Hep.vacciney	0.7647578	0.2500315	1.9081172
PHx.of.jaundicey	1.0458542	0.3409839	2.6240732
Body.ear.piercingy	0.9250094	0.4003907	2.4217032
drugs	2.3190547	0.501001	7.9218049
alcohol	0.9343778	0.4677277	1.7558643

Regional HBV and HCV testing data in Surrey 2013:

I used anonymised testing data from regional laboratory data to identify testing practice for HBV and HCV in primary care across Surrey. Approximately 14% of requests could be categorised into one of the conventional case-finding indications (figure 1).

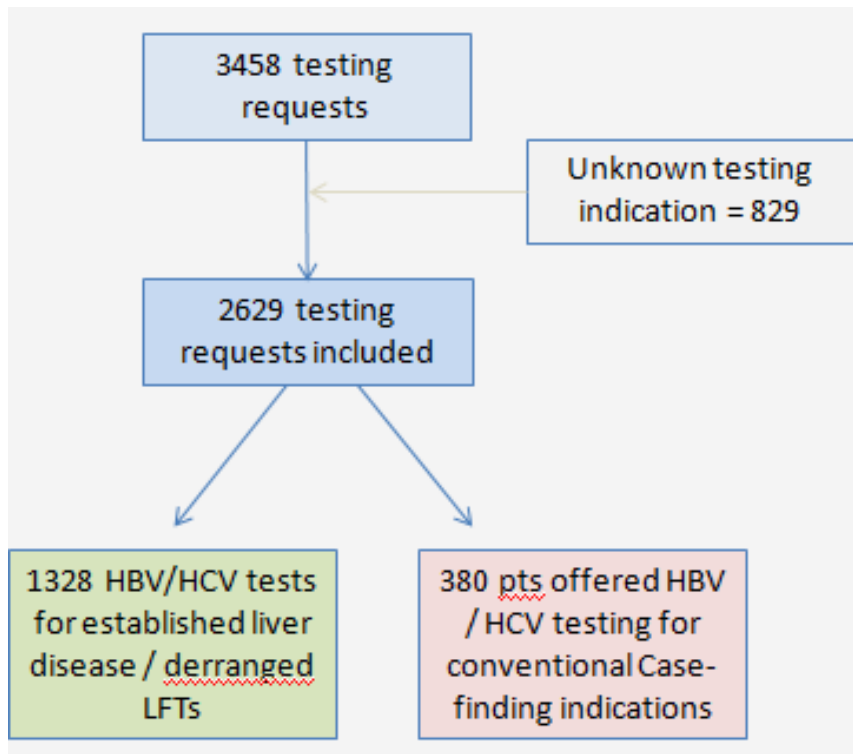


Figure 1: Analysis of primary care requests for HBV and HCV in 2013.

Household contact-tracing for Hepatitis B

I have also looked at rates of household-contact tracing for HBV, which is an important target in hepatitis B, and driven by primary care testing requests. I collected data on HBV testing over the past ten years, looking at over 110,000 HBV testing requests. Where postcode and address data could be effectively identified, there was no evidence of household testing in over 70% of HBV positive individuals. This work has been accepted to present at the upcoming Digestive Diseases Federation meeting in June 2015.

Boundary-spanning activity working with the British Liver Trust

We collaborated with the British Liver Trust to build upon their national “Love Your Liver” campaign, providing work-based questionnaires to all employees identifying the key risk factors for liver disease: alcohol excess, obesity and viral hepatitis. Working with Siemens, I undertook an in-house clinic offering counselling and a dedicated liver USS and elastography (non-invasive assessment of fibrosis) to all employees who wished to attend during the day. 9 slots were granted to staff members during the day, and we were not able to fulfil the number of review requests. The event was publicised through the British Liver Trust and Siemens, with a publicity video where I discuss the burden of liver disease in the UK:

http://www.siemens.co.uk/en/insights/liver_disease.htm

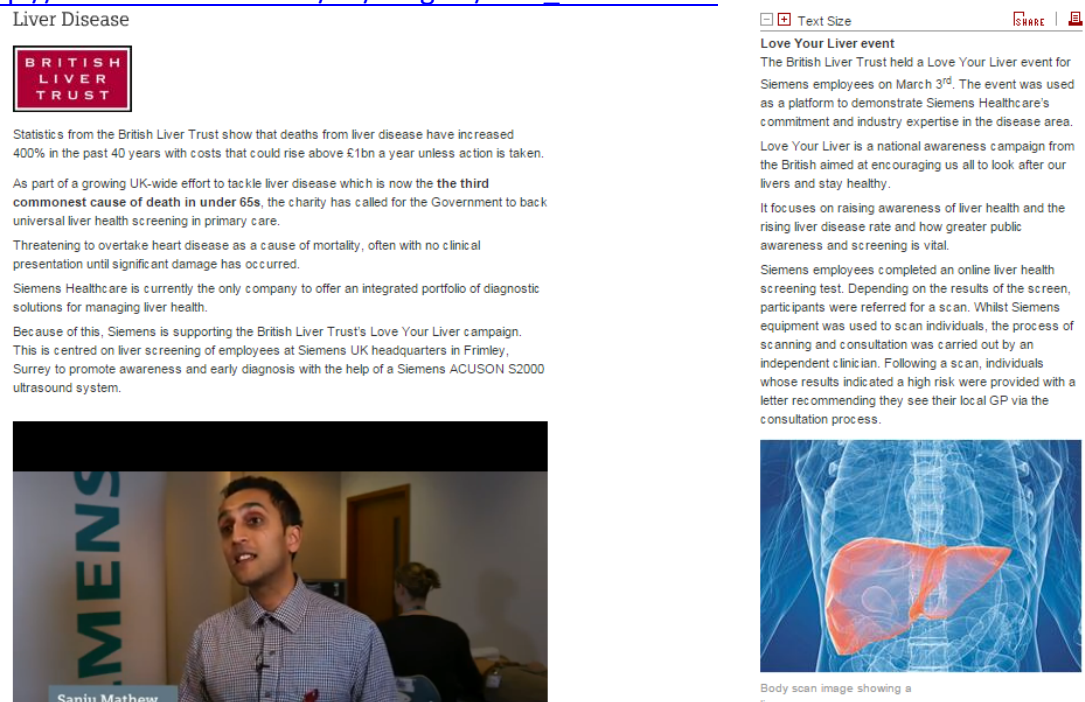


Figure 1: screenshot of boundary spanning activities taken from the Siemens Love Your Liver day. The session was successful in identifying a high level of interest among employees, and utilised the support of the employer to promote questionnaire uptake. Working with a patient charity group also afforded a large amount of publicity and volunteer support to increase the profile of the session, with designated “liver champions” that were on hand to spread the message of liver disease and the importance of risk-modification. Employers are perhaps also more likely to participate with patient charity groups, as this may tap into dimensions of corporate social responsibility and the direct and indirect benefits of “employee wellbeing”.

Staff participating in the study were given designated leave periods to come and see me for a confidential discussion of any concerns, and for a designated liver scan. Out of 9 “clinic” discussions (held in a makeshift room), we identified 2 people with possible liver fibrosis on imaging, and who had clear risk factors from the associated questionnaire. Alcohol and obesity were the likely risk-factor in these individuals, but despite clear risk profiles, this session was the first time that these risks were discussed, and that liver disease was mentioned to these individuals.

Whilst some individuals may be reluctant to engage with health discussions in the work place, this multidisciplinary approach represents a successful and potential approach to reaching some groups of the population.



Ms Gill Fairbairn
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Email: HRA.CAG@nhs.net

27 January 2015

Dear Ms Fairbairn

Study title: A Feasibility Study of Case-Finding Strategies for the Detection
of Hepatitis B and C in Primary Care
CAG reference: 14/CAG/1013

Thank you for your research application, submitted for approval under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process patient identifiable information without consent. Approved applications enable the data controller to provide specified information to the applicant for the purposes of the relevant activity, without being in breach of the common law duty of confidentiality, although other relevant legislative provisions will still be applicable.

The role of the Confidentiality Advisory Group (CAG) is to review applications submitted under these Regulations and to provide advice to the Health Research Authority on whether an application should be approved, and if so, any relevant conditions. This application was considered on 24 July 2014.

Health Research Authority approval decision

The Health Research Authority, having considered the advice from the Confidentiality Advisory Group as set out below, has determined the following:

1. The application is approved, subject to compliance with the standard and specific conditions of approval.

Context

Purpose of application

This application from the University of Surrey set out the purpose of a study which aimed to compare three testing strategies compared to usual viral hepatitis testing practice in primary care (GP practices).

A recommendation for class 1, 4 and 6 support was requested to cover access to confidential patient information from GP practice records by a researcher in order to help with patient identification for the study. MIQUEST queries would be set up to allow the extraction of pseudonymised data for follow up purposes only and a researcher may require access in order to set this up. This would be undertaken only where necessary and

1. Favourable opinion from a Research Ethics Committee **Confirmed 25/09/2014.**
2. Confirmation of suitable security arrangements via IG Toolkit submission.
Confirmed 29/12/2014.

As the above conditions have been accepted and/or met, this letter provides confirmation of final approval. I will arrange for the register of approved applications on the HRA website to be updated with this information.

Annual review

Please note that your approval is subject to submission of an annual review report to show how you have met the conditions or report plans, and action towards meeting them. It is also your responsibility to submit this report on the anniversary of your final approval and to report any changes such as to the purpose or design of the proposed activity, or to security and confidentiality arrangements. An annual review should be provided no later than 19 November 2015 and preferably 4 weeks before this date.

Please do not hesitate to contact me if you have any queries following this letter. I would be grateful if you could quote the above reference number in all future correspondence.

Reviewed documents

The documents reviewed at the meeting were:

Document	Version	Date
Covering letter on headed paper		01 July 2014
Letters of invitation to participant		14 July 2014
Other [CAT advice form]		14 July 2014
Other [Sensitive data sheet]		14 July 2014
IRAS Application Form		14 July 2014
Research protocol or project proposal		01 July 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language		14 July 2014

Membership of the Group

The members of the Confidentiality Advisory Group who were present at the consideration of this item are listed below.

There were *no* declarations of interest in relation to this item.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R & D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Group's best wishes for the success of this project.

Primary care case-finding – developing electronic coding strategies to identify at-risk groups –
MIQUEST Coding (tested in regional GP practices in KSS)

ASIA		Africa		
Ethnic category 2001 census		File		
Indian or British Indian	9i7..	04ETCNAS	African	9iC..
Pakistani or British Pakistani	9i8..		Somali	9iD0.
Bangladeshi or British Bangladeshi	9i9..		Nigerian	9iD1.
Chinese	9iE..		North African	9iFA.
Vietnamese	9iF0.		Moroccan	9iFF.
Japanese	9iF1.		Mauritian/Seychellois/Maldivian/St Helena	9iFJ.
Filipino	9iF2.			
Malaysian	9iF3.			
non-census coded				
South East Asian	9T1B.	08ETNC		
Indian	9T1D.			
Chinese	9T1C.			
Nepali	9T9..			
"born-in"				
Born in Pakistan	13eW.	09ETBIAS	Born in Egypt	13gE.
Born in Afghanistan	13e0.		Born in Algeria	13g0.
Born in Bangladesh	13e3.		Born in Ethiopia	13gG.
Born in China	13e8.		Born in Ghana	13gJ.
Born in India	13eD.		Born in Kenya	13gN.
Born in Indonesia	13eE.		Born in Malawi	13gS.
Born in Malaysia	13eP.		Born in Morocco	13gV.
Born in Nepal	13eT.		Born in Nigeria	13gZ.
Born in Philippines	13eY.		Born in Somalia	13ge.
Born in South Korea	13ee.		Born in South Africa	13gf.

PERCEPTIONS OF LIVER DISEASE AMONGST THE NEPALI COMMUNITY; DESIGNING EFFECTIVE CASE-FINDING STRATEGIES TO TEST UK MIGRANT GROUPS FOR HBV & HCV

Sanju Mathew^{1,2}, Mihaela Petrova¹, Jane Hendy², Joanne Zamani³, Melvyn Dunstall³, Margot Nicholls³, Lisa Moore¹, Patrick Kennedy⁴, Graham Foster⁴, Aftab Ala^{1,5}

1. Department of Gastroenterology & Hepatology, Frimley Park Hospital NHS Foundation Trust; 2. Dept of Health Care Management & Policy, University of Surrey
3. Surrey & Sussex Health Protection Team, Public Health England; 4. Queen Mary's University, University of London
5. Faculty of Health & Medical Sciences, University of Surrey

Results:

32 Nepali members took part in focus group sessions lasting 30-60 minutes

Causes of Liver Disease:

"It comes from our food, we also hear that Witch person can give the disease"

"It is due to polluted water, the most is due to polluted food"

"No it is not communicable in my opinion", "Genetic, not a communicable disease"

"Spirit also invade people resulting in liver disease, people says so. If Spirit support you then the disease is cured"

Treatment Experiences / Knowledge:

"It is said that herbal medicine best, but does not cure disease completely"

"There are many stories where witch doctor treated jaundice. Modern medicine and injections are really bad for jaundice. I have even seen a British Army Officer in Dharan, Nepal treated by a Witch doctor, and he was completely cured"

Learning more about liver disease:

"GPI We go to our GP"

"What the doctor said, we trust on it. Whatever he says we trust him, we do not know more"

- Liver disease is attributed most commonly to polluted food and water, perhaps as a manifestation of Hepatitis A contraction in Nepal. All elderly groups concurrently give firsthand accounts of having had transient bouts of jaundice when younger in Nepal
- Worringly many cite non-communicable causes for liver disease, with both younger and older groups attributing externalising forces from Witch doctors and Spirits
- Younger groups associate greater stigmatisation towards liver disease, linking this with alcohol and prostitution

Implications:

The local Nepali community is keen to engage with health education and testing for liver disease
Although there are strong traditions of externalising forces causing disease, and homeopathic remedies, there is a dual acceptance and interest in engaging in modern medical models of disease

We have used this information to establish community testing sessions in local centres with great success to date, engaging with community leaders to reach large numbers of the local community

- The Nepali population in the UK has grown rapidly since 2004 when settlement rights were granted to ex-Gurkha servicemen and their dependents; a policy further expanded in 2009 with popular public and celebrity support
- The current UK population is 60,000; a growth of over 969% since the 2001 census⁽¹⁾
- Communities are concentrated around military bases, and Hampshire County now has the second largest Nepali community in the UK, making up close to 10% of the local population in some areas

- Nepal sits between China and India, two countries with a higher prevalence of viral hepatitis (namely HBV), and higher HCV rates are well-recognised in the South Asian population
- The health needs of this new population is unknown with concerns that there may be higher rates of viral hepatitis, which can lead to end-stage or advanced complications if left untreated

- Migrant groups represent a "hard-to-reach" population for case-finding with complex socio-cultural and religious factors that influence health-seeking behaviour⁽²⁾

Aims:

Culturally-appropriate testing strategies are crucial to developing successful engagement; both for testing and future therapeutic management

As part of our aim to facilitate a large scale testing programme for members of the Nepali community, we first held focus group workshops to study the understanding and perception of liver disease within the Nepali community

Methods:

Bilingual Nepali speaking moderators (Nurses) conducted 4 Focus-Group sessions

Groups were divided according to age and sex

Males < 30 years
Males > 30 years
Females < 30 years
Females > 30 years



A Nepali Shaman

References:

1. Centre for Nepali Studies UK: ONS data
2. Nirradhan 2009. Migrants: use of domestic healthcare services in Europe. BMC Public Health

Images: Major Damar Chole



PERCEPTIONS OF VIRAL HEPATITIS TESTING IN MIGRANT COMMUNITIES AND THE PRIMARY CARE PHYSICIANS THAT SERVE THEM

Sanju Matthew^{1,2}, Milhaela Petrova¹, Jane Hendy², Simon de Lusignan³, Joanne Zaman¹, Ranji Tiwar², Margot Nicholls⁴, Patrick Kennedy⁵, Graham Foster⁶, Atiab Alai^{1,6}
 1. Department of Gastroenterology and Hepatology, Frimley Park Hospital, UK; 2. Department of Health Care Management and Policy, University of Surrey, UK; 3. Rushmore Healthy Living, Hampshire, UK; 4. Surrey and Sussex Health Protection Team, Public Health England; 5. Queen Mary University, London; 6. Faculty of Health and Medical Sciences, University of Surrey, UK



BACKGROUND

- Migrant communities are disproportionately affected by HBV & HCV, with 95% of all UK chronic HBV cases thought to lie in the Migrant community
- Despite existing national and international policy, case-finding practice is thought to be poor throughout Europe.
- The burden of CVH lies in the community, and the perceptions and engagement of Primary Care Practitioners (PCP) will be crucial in any attempt to improve case-finding.
- Members of migrant communities have known difficulties in healthcare engagement that is not limited by knowledge alone
- Migrant populations are heterogeneous both in disease prevalence and in perceptions to disease and healthcare.
- New migrant groups present unique challenges;
 - The UK Nepali community represents such a group, with little known about underlying disease prevalence, nor how to successfully engage with this "new" population

MATERIALS & METHODS

- 4 Focus Group sessions were held with members of the Nepali community (n=32) divided by age and sex in South East England

Males < 30 years	Females < 30 years
Males > 30 years	Females > 30 years
- Focus group sessions were then held with 3 GPs of varying seniority (1 GP registrar), that serve this new Migrant community
- An Applied Thematic Analysis approach was used for data interpretation

RESULTS

MIGRANT FOCUS GROUP – THEMES (SUMMARY)

Causes of Liver Disease:

- "It comes from our food, we also hear that Witch person can give the disease"
- "It is due to polluted water, the most is due to polluted food"
- "No it is not communicable in my opinion"; "Genetic, not a communicable disease"

Treatment Experiences / Knowledge:

- "It is said that herbal medicine best, but does not cure disease completely"
- "There are many stories where witch doctor treated jaundice. Modern medicine and injections are really bad for jaundice...."

Learning more about liver disease:

- "GP! We go to our GP"
- "What the doctor said, we trust on it. Whatever he says we trust him, we do not know more"

PRIMARY CARE PHYSICIAN – THEMES (SUMMARY)

Current Practice

- "We test people with abnormal LFTs, symptoms..."
- "...we don't have a policy for screening new registrations...."
- "NICE has probably done something, but I haven't read it!"

Perceptions on HBV/HCV testing:

- "I thought everyone had already been tested for hepatitis C"
- "It's all being done anyway...we screen all the antenatals don't we,?"
- "...there is a kind of barrier, cultural or language already...it can cause offense."
- "...is it not going to be judged as prejudiced against one racial group?"
- "Screening has harms as well as benefits...implications for family members...insurance..."

Barriers to testing:

- "We are overwhelmed with workload...haven't got capacity unless there's some money involved...."

DISCUSSION

- Among PCPs, knowledge and practice regarding case-finding was generally poor, with no GP aware of recent NICE case-finding guidance (2012), despite its wide circulation.
- Migrant testing was expressed as a burden, and of low priority by most. Many PCPs were concerned that Migrant case-finding would be viewed as "racial profiling" and would "cause offense".
- Several PCPs felt testing posed "harms" in relation to insurance premiums and family impact if a positive case was discovered (rather than contact-tracing benefits).
- Members of the Nepali community on the other hand were universally keen to learn more about liver disease and to engage with testing, especially via Primary Care.
- Strong externalising factors were raised (principally spiritual) in liver disease aetiology and therapies, and few mentioned potentially stigmatising factors.

Future case-finding approaches in primary care may be improved with the inclusion of Migrant Community Leaders to support PCPs, and to raise awareness for testing in the community. However this will require the provision of dedicated funding/resources to manage what is likely to be a high uptake in testing.

OBJECTIVES & METHODS

- To investigate the awareness and perception of liver disease and CVH among members of the UK Nepali community
- To understand perceptions related to aetiology and epidemiology of liver disease or CVH that may influence future case-finding strategies.
- To contrast the awareness and perception of CVH and case-finding in Primary Care Practitioners (PCPs, GPs) that serve this new migrant community



Supported by the National Gilead Fellowship Award, and the National Institute for Health and Research, UK

Reference: NICE PH 43, Hepatitis B and C: Ways to promote and offer testing to people at increased risk of infection. (Picture: Major Damer Chahal)

DEVELOPING MODELS OF ENGAGEMENT IN A NEW MIGRANT POPULATION: A LARGE SCALE HEPATITIS B & C TESTING STUDY IN THE UK NEPALI COMMUNITY

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BACKGROUND

The UK Nepali community is a new and unique migrant group, which has grown by over 900% since the granting of settlement rights to ex-Gurkha servicemen and their dependants.

Rates of viral hepatitis B & C (HBV, HCV) are unknown in this UK community, with higher rates of disease seen in the bordering countries of India & China

Testing in migrant communities is recommended in NICE guidance, but with many first generation migrants representing a hard-to-reach population, - with higher rates of disease prevalence and complications seen in this group

Little is known about health perception in this community, or how to engage with and offer testing to this population, which has multiple faith and caste denominations

We therefore undertook a large-scale study to understand the perceptions of liver disease in this population, and to develop a community engagement strategy to identify the HBV and HCV prevalence in this new migrant group

MATERIALS & METHODS

- Focus group sessions were held first, using Nepali moderators to help understand disease perception, and to develop culturally-appropriate community testing strategies.
- Community venues were chosen central to known population clusters, with peer-advocate support, and Nepali language advertising on local radio networks.
- DBS finger-prick blood testing was utilised for:
 - HBsAg, HB core Antibody and HCV Antibody
- Risk-questionnaires were assessed with each participant

How many adults live in your household? How many children live in your household?

Have you ever had any of the following? ☐ Yes ☐ No ☐ N/A Details

Blood transfusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, when?
Surgery abroad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, when?
Dental work abroad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, when?
Vaccination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, when?
Hepatitis vaccination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A/B/C (date)
Past history of jaundice or hepatitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	A/B/C (date)
Family history of hepatitis / liver disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, for how long?
Body or ear piercing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, for how long?
Use of recreational drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If Yes, for how long?
Sensible or binge drinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	> 21 (M) or 14 (F) units weekly

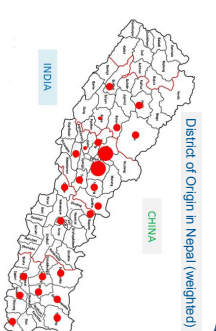
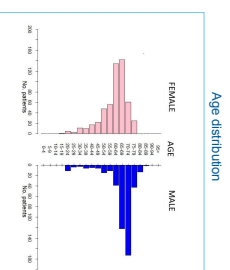
RESULTS

STUDY POPULATION

- 1005 Nepali individuals were tested over 17 sessions from March 2013 - January 2015
- 973 individuals were included in the final analysis

Age (mean)	63 yrs (19-86)	Blood transfusions	8%
Males	45%	Surgery abroad	34%
Months in UK	36 months (Median)	Piercings	91%

- Only 1.8% (18 individuals) had been in the UK > 10 years



• VIRAL MARKERS

HB s Ag +	3 / 973 (0.31 %)
HCV Ab +	4 / 973 (0.41 %)
HB core Antibody	93 / 973 (9.6 %)

- Low rates of HBsAg & HCV Ab prevalence
- Higher rates of HBcAb prevalence

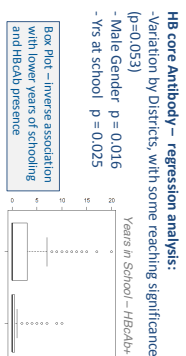
- Hospital Clinic F/Up (via GP referral) - 5 / 7 patients

HBV DNA < 300 IU/ml	4 / 973 (0.41 %)
HCV RNA Negative	93 / 973 (9.6 %)

No evidence of sig. Fibrosis/Cirrhosis (USS, Fibroscan)

Regression Analysis (HBsAg, HCV Ab)

- No statistically significant risk-factor associations in those (few) patients identified with HBsAg / HCV Ab



Discussion

- Rates of active HBV and HCV infection are low in the study population
- But rates of previous HBV exposure (HBcAb) are high, with lower years of schooling and male gender statistically associated with this.
- Variation in HBcAb positivity is seen according to district of origin, but without reaching statistical significance
- The Nepali community has multiple castes and religious groups, and has encountered significant stigma from right wing groups and local media sources in keeping with many new migrant communities in the current climate
- Working with peer-advocates and community leaders we have developed a successful model of engagement to build strong links with this large diverse community, with strategies that can be adopted to other migrant communities and health settings.

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PERCEPTIONS OF VIRAL HEPATITIS TESTING IN MIGRANT COMMUNITIES AND THE PRIMARY CARE PHYSICIANS THAT SERVE THEM

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Do you want to apply for a Young Investigator Bursary?: No

Background and Aims: Migrant groups are disproportionately affected by hepatitis B and C (CVH). Effective community testing must be culturally-appropriate, and ideally include informed testing in primary care. General Practitioners (GPs) offer a direct and effective route for community testing, but participation is thought to be poor, with little study into the awareness, understanding and perception of GPs towards CVH case-finding. We conducted focus group sessions among members of the Nepali community; a new and unique community to the UK, as well as GPs to study and contrast the awareness and perception of both groups to CVH and CVH testing.

Methods: We conducted 4 focus group sessions in the Nepali community; divided by age (greater/less than 30 years) and sex. We explored the understanding and perception of liver disease and viral hepatitis, including developing new testing strategies. We also conducted focus group sessions among GPs from 2 large General Practices in South East England that serve this growing Nepali community. We explored the understanding and perception of viral hepatitis case-finding, including recent national testing guidance.

Results: 32 members of the Nepali community took part in focus group sessions. A strong extrinsic association was seen related to most concepts of liver disease, including spiritual causes/cures and food pollution. Younger groups associated a greater degree of stigmatisation towards liver disease from alcohol or prostitution. However all groups wanted to engage with liver disease education and testing, and universally so via primary care services.

9 GPs of varying seniority, from military and civilian backgrounds took part in the focus group session. Overall CVH testing was viewed as a low priority, with one senior GP expressing that they had not seen a single case in the past 20 years. No GP was aware of national case-finding guidance, despite its recent release and community focus. Migrant testing was not offered by any GP, with the feeling that this would be viewed as "racial profiling" by members of the migrant community.

Conclusions: Members of the Nepali community expressed universal interest in engaging with primary care to learn more about liver disease and testing. However, the GPs in the same area viewed CVH case-finding as a low priority, with little awareness of national or international guidance for migrant testing. Stigmatisation was raised by some younger members of the migrant focus group, but was almost a universal concern to GPs.

Disclosure of Interest: None Declared

ddd

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HEPATITIS B TESTING PRACTICE: HOW WIDESPREAD IS HOUSEHOLD CONTACT TRACING?

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Is your abstract a video?: No

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Do you qualify and would you like to apply for the DDF travel bursary: No

County of Residence: United Kingdom

Introduction: Contact tracing in hepatitis B (HBV) is nationally and internationally advocated. Acute HBV is managed by Public Health England (PHE). However, the expectation and responsibility for contact tracing in chronic HBV lies predominately with primary care, with no formal implementation strategy or monitoring system in place.

Method: The Surrey Pathology Partnership serves over 1million individuals in South East England. We collected laboratory data from the past 10 years on all Hepatitis B Surface Antigen (HBsAg), and Core Antibody (total HBcAb) testing requests, to assess the uptake and efficacy of contact-tracing amongst those with HBV. We identified address and postcode data from hospital and community-based testing requests (excluding anonymised GUM data) to identify those individuals who had undergone household contact-testing for HBV.

Results: In total, 119,873 HBV (HBcAb +/- HBsAg) tests were undertaken between Jan 2005 and Jan 2015; 69,256 HBsAg tests (+/- cAb) were subsequently identified with appropriate address and postcode information. HBsAg was detected (positive) in 851/69,256 laboratory requests (0.01%); median age 36 years, Female 55%, with 661 individual patients diagnosed with HBV in this period (HBcAb+ 77%).

Clinical indications for testing and the requesting speciality were poorly documented, but antenatal HBV testing was the predominant indication/specialty with 23,719 requests.

159/661(24%) of HBsAg-positive cases were detected in primary care, 395/661 (60%) in Hospital outpatients (Gastro/Hepatology); 10/661 (1.5%) in Antenatal services and 3/661 (0.45%) in Prisons.

814 unique patient addresses were identified for 661 HBV positive patients; 54 HBV positive patients shared the same address (26 households, range 2-3 /household), with an additional 203 negative HBsAg requests made in the remaining household contacts, with HBcAb evident in 18% of these individuals.

Conclusion: NICE public health recommendations were issued in late 2012 to guide HBV testing practice, but its uptake is thought to be poor, and our data highlights the deficits that exist in contact-tracing, with close to 70% of household-contacts not offered testing.

Although there are data-deficits to using recorded laboratory data, it provides a readily available and reproducible format to identify and monitor regional contact-testing practice. We hope to use this format to guide and monitor regional testing strategies.

Disclosure of Interest: None Declared

