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Identifying factors influencing practitioners' role in access to health care for hepatitis B in Chinese populations in England

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Abstract

Background: Access to health care for chronic hepatitis B (CHB) is poor in migrant populations of Chinese ethnicity in England. Previous worldwide studies focusing on this problem have largely addressed population factors with few studies focusing on practitioner roles and service-related factors. The aim of this study was to identify and explore practitioner and service related barriers and facilitators to access to health care for CHB affecting Chinese populations in England.

Methods: Semi-structured interviews were conducted with 21 frontline health care practitioners and two key informants to examine practitioners' roles, attitudes and practices in relation to CHB and with Chinese populations. Thematic interpretive analysis was undertaken to identify modifiable factors in primary and secondary care and wider service factors. Relevant models guided design and analysis.

Results: Factors were identified at individual practitioner level, during interaction with patients and at organizational level. Practitioners balanced complex responsibilities and CHB is low in their priorities. Professional principles, skills and knowledge are not sufficient in facilitating access in the face of clinical uncertainty, unclear policy and conflicts in funding that reflect structural barriers. Factors acting in the interaction with patients include difficulties with interpreters and understanding patient expectations from services. Facilitators were identified and included bespoke services and active interaction with

Chinese community services. Organizational issues including increasing workload, lack of support and financial limitations and conflicts, were also acting as barriers to appropriate identification and referral of patients.

Conclusion: Practitioners balanced numerous demands that may hamper the decision-making process, hindering the role of facilitating access to care for asymptomatic, low priority conditions. Individual patient preferences could be addressed more effectively using cross-cultural care approaches. In addition, addressing dimensions of structural racism, including the lack of effective access pathways, lack of practical support and of dissemination of clinical guidance could help address service barriers.

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Frequently used abbreviations and acronyms

Acronym	Definition
CHB	Chronic Hepatitis B
GP/GPs	General Practitioner/s
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PC	Primary Care
SC	Secondary Care
USA	United States of America
UK	United Kingdom of Great Britain (England, Wales and Scotland) and Northern Ireland

Introduction

The introduction describes the context of this study and the contents of this thesis. This study employs a qualitative enquiry method to find factors that relate to, or influence the roles of, health care practitioners and have the potential of facilitating or hampering access to health care for chronic hepatitis B in populations of Chinese ethnicity resident in England.

This practitioners' study was part of a wider qualitative study funded by the Department of Health Policy Research Programme to establish factors that facilitate or hinder access to health care services for hepatitis B in individuals of Chinese ethnicity. I follow with an explanation of this context, as this is an important background for this study.

The Department of Health bid, launched in September 2012, commissioned studies to address liver health issues in the UK. The main aim was to address undiagnosed chronic viral hepatitis B or C in people at risk of infection. The wider study was funded to provide evidence of factors influencing lack of testing and treatment for hepatitis B for people at risk in order to inform policy and interventions in support of the upcoming liver disease strategy (Department of Health, 2010; Williams et al., 2014). The study was approved in late 2013 and commenced in 2014. It incorporated a systematic review of the literature, and a qualitative exploratory study *(Department of Health ref.: PRP 015/0313 - Identifying interventional approaches to improve health care access for Hepatitis B in high prevalence groups. A study of knowledge, beliefs, and attitudes about Hepatitis B among Chinese and Far East Asian residents of South Yorkshire and* *factors restricting appropriate risk evaluation, testing, preventative activities and referral for treatment to inform review of current policy)*.

The qualitative study included focus groups with individuals of Chinese ethnicity and interviews with key informants including patients attending chronic hepatitis B services, community key workers, health care practitioners and health service commissioners and policy makers. It was carried out in three stand-alone study arms led by members of the study group. Dr Eva Liu (PhD anthropology) and Professor Sarah Salway (senior social scientist) led the community arm using six focus groups discussions and 20 semi-structured interviews with community key informants. The practitioners' study involved 23 individual interviews and was carried-out by myself, Dr Alicia Vedio (physician and chief investigator). Dr Andrew Lee and Dr Jason Horsley (public health consultants) undertook nine semi-structured interviews with commissioners and policy makers. The completed study report was submitted to the Department of Health in March 2017 but it had not been published by the time this thesis was submitted. Two main open access publications derived from this study, a systematic review (Vedio et al., 2017) and a study of determinants of access to health care (Lee et al., 2017).

The wider study was the initial stepping stone to explore the available practitioner's data further. The wider study analysis focused on integrating data of the three arms of the study to elucidate interdependent barriers of access to health care (Lee et al., 2017). This study was undertaken to explore service and practitioners' factors in further depth, and to incorporate the theoretical models described in Chapter 1. This thesis aims to represent and reproduce the in depth exploration and discussion of front line health care practitioners' perspectives and experiences that could contribute to the identification of modifiable barriers and to current discussions around improving health service practices that address underserved populations. The data was subjected to further analysis using theoretical models of access to health care, shared decision-making and cross cultural communication models to help identify modifiable factors that could inform practice and further research. Organizational issues were explored through the lens of structural racism. The wider study data from the community and policy makers and commissioners' arms informed this thesis by providing points of reference for the data analysis and interpretation.

The following paragraphs describe the content of each chapter.

Chapter 1 sets the background of the study and highlights the relevance of studying barriers of access to health care services for chronic hepatitis B by Chinese populations resident in England. The first section presents hepatitis B infection public health concerns, clinical background and epidemiological data in Asian high prevalence regions and in England and Wales. The second section gives an overview of Chinese populations residing in England and Wales. In this section the concept of ethnicity is introduced, and the literature about access to health care services in general in the UK and for hepatitis B in the UK and worldwide for populations of Chinese ethnicity is examined. A third and last Background chapter section explores the theoretical models of access to health care that guided the study. This section includes other models that were used to expand the concept of access - shared decision-making, concepts related to cross-cultural care and structural racism - and describes their relevance for this study.

In Chapter 2 the published evidence on the influence of practitioners on access to healthcare for Chinese or East Asian populations for CHB is reviewed and synthesised. This literature review was performed to elucidate what is already known on the topic and to inform the study. The review adopted a mixed method approach and includes 11 publications that addressed practitioner factors from worldwide literature in English language.

Chapter 3 describes and justifies the research perspective and methods used in the study. This was a qualitative study, using semi-structured interviews to generate insights from clinicians working in diverse areas of the health service. The philosophical stance used is subtle realism and the data analysis adopted an interpretive approach based on thematic analysis. At the end of Chapter 3, the descriptive findings set the scene for Chapter 4. The section examines the setting of the study by describing demographic data, context of work, and provides an overview of initial indexing of data.

Chapter 4 presents the constructs and interpretation of the data, aiming to make sense of insights and meanings of practitioners' narratives. The chapter is organized in three categories of interpretive findings. The categories correspond to individual principles and values, interaction with patients during the clinical encounter, and wider organizational factors including institutional support, commissioning, policy and structural factors. Each category contains interpretive themes and subthemes.

Chapter 5 summarizes the key findings and discusses these in relation to existing literature; strengths and limitations of the study are discussed; explores how the methods and analysis affect the findings; and explains what factors have not been explored. In addition, it discusses the implications for practice, policy and future research and provides a conclusion.

Supplementary information for each chapter is found in Appendices 1 to 6.

1. Background

This chapter introduces the key theoretical and substantive context for the current study in three sections.

First, a description is provided of the essential clinical and public health knowledge needed to understand chronic hepatitis B. This includes complexity of the condition, variations in worldwide prevalence, prevention strategies, possible complications and advances on treatment. The second section provides an overview of the population and a description of health care access profile for people of Chinese ethnicity living in England and Wales. Finally, the third section describes the process of defining access to health care using models that support understanding of barriers and facilitators related to health care practitioners.

1.1. Chronic hepatitis B

Chronic hepatitis B is a long-term infection affecting the liver and characterized by being asymptomatic. Understanding the characteristics of chronic hepatitis B is essential to understand the difficulty in identifying the need for diagnosis and how this may act as a barrier for more vulnerable populations. What follows is a brief summary of the characteristics of the condition.

Introduction

Chronic hepatitis B is a complex condition that can cause significant morbidity in the long term and early mortality due to complications such as liver cirrhosis and liver cancer (Yim et al., 2006). Chronic hepatitis B is a viral infection acquired mainly at birth, infancy or in early childhood (up to 5 years of age) and it is life long in the majority of cases that are acquired early in life (Trépo et al., 2014).

Approximately 25 to 40% of people affected by chronic hepatitis B develop life-threatening complications such as liver cirrhosis or liver failure, and approximately one in 50 will develop liver cancer in their lifetime and this figure is higher in men (Yim et al., 2006; Perz et al., 2006). Presentation with advanced liver disease or liver cancer not only exerts complex demands on the health service, but also significantly reduces life span and quality of life in survivors (Liu et al., 2016). Early diagnosis therefore has significant advantages for the individual affected including the option of assessing the risk for early complications or providing treatment to reduce these.

Chronic hepatitis B differs from acute hepatitis B

Chronic hepatitis B is complex and can present difficulties during assessment of risk in the process of diagnosis. When practitioners assess risk for chronic hepatitis B it is important to distinguish it from acute hepatitis B infection, which is a short-lived disease (less than 6 months) that is more easily recognised and better known to public and professionals, although much less common (Trépo et al., 2014). Acute hepatitis B is mainly transmitted horizontally, this means between older children or adults through contaminated blood and fluids, for example sexually, sharing sharps (i.e. shaving equipment) or needles, or from insufficiently sterile health care practices (examples: untested blood transfusion, re-use of needles or dialysis tubing or filters) or during traditional cuttings. The acute form is seen mainly in older children (> 5 years of age) or adults and can produce intense symptoms such as malaise, abdominal pain and jaundice. Although the acute form is very infectious, it rarely becomes chronic, 95 to 99% of all infections resolving before 6 months (McMahon et al., 1985).

Instead, chronic hepatitis B is mainly transmitted vertically (this is a mother to child transmission before or during birthing), and in infancy or early childhood (before 5 years of age). The chronic form usually does not have an acute phase with symptoms or signs such as jaundice (Trépo et al., 2014). The lack of symptoms can make it more difficult to diagnose at an early stage (Fattovich et al., 2004). A proactive clinical decision to test for the infection is usually necessary, as described in the national pathway for clinical care (National Institute for Health and Clinical Excellence, 2012). In addition, early diagnosis has benefits from a public health perspective, because there are effective ways of preventing the spread of the infection to close contacts or any susceptible individual by immunization (Locarnini et al., 2015).

Chronic hepatitis B is more common in certain areas of the world. Information about the differences in prevalence of HBV and its relevance is summarized in the next section.

1.1.1. Overview of hepatitis B prevalence

Hepatitis B is the most common and most infectious blood born virus; it is globally distributed but rates vary throughout the world (World Health Organization, 2013). Worldwide, chronic hepatitis B is estimated to affect between 240 and 250 million people (Ott et al., 2012; Schweitzer et al., 2015).

The infection rate in countries is categorized by the World Health Organization into high (8% and higher), high intermediate (5% to 7.99%), low intermediate (2% to 4.99%) and low prevalence (below 2%). Countries in East Asia (parts of China, Singapore, Malaysia) and in South East Asia (Korea, Vietnam, Laos, Cambodia) are included within high prevalence regions; likewise for the Sub-Saharan African and areas of the Amazonian Basin regions with prevalence of 8% or greater (World Health Organization, 2013). Recent estimates categorize China within high intermediate prevalence countries (between 5% and 7.99%). This change followed the implementation of an universal immunization programme, therefore the reduction is marked in those younger than 16 years (Schweitzer et al., 2015).

In the UK the overall HBV prevalence is below 1%, and migrants from high prevalence areas tend to be more affected (Falla et al., 2014). Interestingly, a recent UK study shows that viral hepatitis B and C prevalence in the country of origin does not always predict prevalence in UK migrants from South Asian ethnicity (Uddin et al., 2010). However, diagnostic testing projects run in locally defined populations have shown that migrant Chinese adults in the UK have similar prevalence as that found in adults in China. Chronic hepatitis B was found in 8% to 12% of those tested in three studies in the UK (Kawsar, 2002; Mcpherson et al., 2013; Vedio et al., 2013). Similar prevalence was seen in the Netherlands (Veldhuijzen et al., 2012) and the USA (Chang et al., 2009; Chao et al., 2009). These findings indicate there is an increased health care need in these groups.

Liver cancer related to hepatitis B virus is the second cause of cancer related mortality in China (Zuo et al., 2015). In the UK, incidence rate of liver cancer in Chinese men is four fold, and that of Chinese women is two fold when compared with white native population, and this correlates with hepatitis B infection (Jack et al., 2013). The national guidelines released in 2012 clearly describe the groups that will benefit from testing and treatment of chronic hepatitis B, and these include people from countries of intermediate and high prevalence. (National Institute for Health and Clinical Excellence, 2012).

Hepatitis B infection is preventable, many countries have strived to reduce their prevalence by implementing universal immunization, and this is discussed in the next section.

1.1.2. Chronic hepatitis B is a preventable disease

Hepatitis B can be effectively prevented through immunization (Szmuness et al., 1980; Beasley et al., 1983). Immunization is the most important measure to protect people unaffected by the HBV infection, especially close contacts of people infected, workers with occupational exposure to blood and other individuals at risk (Locarnini et al., 2015).

In high prevalence countries, immunizing every infant through universal programs can reduce the country's hepatitis B prevalence in the long term. The World Health Organization in 1992 recommended that the hepatitis B vaccine be incorporated to the childhood schedule worldwide. This call followed the recommendations in the USA (Center For Disease Control, 1991). China, among other countries, pledged to this recommendation in 1992 and instituted a more robust programme ten years later. A national sero-prevalence study carried out between 2006 and 2007 in China demonstrates that prevalence decreased significantly to below 2% in children younger than 5, those aged 5 to 20 had also a decreased prevalence between 3 and 6%, but those aged 20 and above had, as expected, a high prevalence of 8 to 10% (Liang et al., 2009).

When our study was done, in 2015, neonatal immunization for hepatitis B in England was targeted to babies born to mothers with hepatitis B. Targeted immunization of babies born to mothers with hepatitis B was initiated at birth in secondary care within 12 hours of birth. The follow-up immunizations for babies born before August 2017 were transferred to primary care to complete the one-year course of four doses independently from, and in addition to the normal infant immunization schedule. Many barriers contributed to ineffective completion of targeted immunization, with the untoward consequence of vertical acquisition of chronic hepatitis B in the infant (English, 2006; Bedford, 2015). An example of a dedicated service developed in London, England, addressed these barriers (Larcher et al., 2001). Larcher's controlled intervention was successful in completing immunization in 242 of 265 infants born to mothers with chronic hepatitis B over a five-year period. This was a much-improved outcome in comparison to a control neighbourhood. The barriers to completing the course identified in the study were high mobility, unexpected baby surname changes and poor understanding of the need for immunization. It must be considered that despite the institution of universal immunization some of these barriers may still be significant.

England included HBV immunization in the general infant immunization schedule since 1st August 2017 (Public Health England, 2017). Extra initial doses at birth and one month are still necessary for babies born to mothers that test positive for the virus. However, the follow-up immunization can be now secured by the UK childhood schedule.

In addition to immunization, timely treatment of chronic hepatitis B can prevent transmission and complications and this is discussed in the next section.

1.1.3. Treatment helps prevent complications and transmission of hepatitis B

After the virus discovery in 1970, and for nearly three decades, understanding of the pathology of chronic hepatitis B was poor and treatment was not available. For this reason, patients were not monitored in the long term, and little intervention was offered (Yim et al., 2006). Much of the newer understanding and new treatments have been developed in the last 20 years. Data showing long term effectiveness of newer treatments are more recent (Trépo et al., 2014). Although current treatments of chronic hepatitis B do not provide a cure, they effectively suppress the virus activity in the long-term. The oral medications that are first line in UK, Tenofovir and Entecavir, prevent and even reverse cirrhosis as early as four or five years into treatment (Chang et al., 2010; Marcellin et al., 2013). In addition the incidence of liver cancer has been shown to reduce although this is not completely eliminated (Papatheodoridis et al., 2015).

Another improved outcome is the prevention of vertical transmission. Treatment during pregnancy completely prevents mother to child transmission in the sub-cohort that still has high risk of transmission to the new-born child despite immunization (Gentile et al., 2014).

These beneficial effects of treatment support the need for early identification of chronic hepatitis B; for these reasons a proactive offer of testing has been recommended in the national guidelines (National Institute for Health and Clinical Excellence, 2012).

Summary

Chronic hepatitis B is a condition that affects high proportion of migrants of Chinese ethnicity, making it one of the most common conditions in this population (World Health Organization, 2013) and liver cancer an important cause of early mortality (Jack et al., 2013; Zuo et al., 2015). Immunization is the mainstay of hepatitis B elimination worldwide and is effective to prevent transmission. Current available treatments provide the benefit of reducing transmission and improving long-term outcomes.

The pathway recommended in the national guidelines considers offering testing to groups at risk, and referral to hepatitis services if the person is affected, or to offer immunization if susceptible to infection (National Institute for Health and Clinical Excellence, 2012). A summary of these recommendations can be found in Appendix 1.2. Individuals with chronic hepatitis B need referral to specialists for consideration of treatment to prevent severe complications that can cause early mortality (Lampertico et al., 2017).

In the next section, I explore the data available from census statistics of populations of Chinese ethnicity living in England. In addition, I discuss the available evidence looking at factors that affect health care access for the same population including worldwide publications on access to health care for chronic hepatitis B.

1.2. Health care access for populations of Chinese ethnicity

This section aims to provide an overview of the population affected by this disparity in access to health care. The first aim of this section is to define the population; then census data for this population is briefly described and, finally evidence around access to health care for this group is discussed.

1.2.1. Defining populations of Chinese ethnicity

The definition of ethnicity in the frame of this research requires clarification. The term ethnicity is a contested research term that is widely used in the UK to indicate groups of people that shared a common cultural background; it overlaps and is used interchangeably with the term race (Salway et al., 2010). As with race, ethnicity is a social and political construct and careful consideration needs to be given in order to understand the term implication in maintaining a power structure (Gunaratnam, 2003), this is discussed further in Chapter 3, Section 3.1.4. For the purpose of this study, groups that were defined as having a common Chinese ethnicity were expected to have wide socio-economic and educational diversity, could be of different nationalities and had different reasons for migration.

The wider study aimed to be inclusive, avoid assumptions and stereotypes of who should be considered Chinese, and to allow individuals to self-define their ethnicity / eligibility for the study. This was discussed during the research meetings with advisory group members, who included people who self identified as being Chinese; it was also discussed during consultation workshops carried out in community centres. In addition, while conducting the community arm of the wider study it was evident that recruitment of self-selected participants included people from countries other than China, Taiwan or Hong Kong. Therefore, this study aimed to represent an inclusive meaning. The rationale of this inclusive approach relates, although not exclusively, to China being the most populated country worldwide, it hosts people of widely different socioeconomic and educational backgrounds, and of diverse origins, languages and cultures. Historically, people from China populated many surrounding countries and has the largest diaspora worldwide (Shen, 2010).

The self-selected sample of participants in the community arm of the wider study included people born elsewhere from parents that identify as Chinese, people from surrounding countries from East Asia that are known to have close ties to China, for example, Vietnam. The recruitment through participants' self-identification of Chinese ethnicity helped formed the basis of the flexible approach that could be applied to the practitioners' study.

In the context of the practitioners' arm of the study, I employed the term 'Chinese' without further clarification in the interviews, leaving it open to interpretation by the respondents. In practice, this led to respondents including people from different nationalities and speaking various languages within their application of this category.

Migration history of people of Chinese ethnicity to England and Wales

This section aims to understand the migration history of people of Chinese ethnicity residing in England and Wales. To understand the current population of Chinese ethnicity, I looked at migration patterns over time from China and Hong

Kong. This search provided a rough idea of numbers and reasons from migration over time but was done with the understanding that this was limited to people born in China and it may not include people of Chinese ethnicity born in countries such as Vietnam, Singapore or other neighbouring countries. The population of Chinese migrants to England and Wales was represented by different episodes over the last century that had significant effect in the characteristics of the population today (Shen, 2010). The Office for National Statistics warned that it is important to note that the nomenclature used in the latest three populations census hindered an assessment of changes in migratory patterns over the last 30 years for Chinese people. The last census strategy aimed to document these more clearly by asking about years since migration occurred (Office for National Statistics, 2015).

Patterns of migrations

In exploring migrations from China to England, there were records of small groups known to have migrated from China to England and Wales as seamen in the 18th and 19th centuries and unskilled migrants in the first half of the 20th century (Xiang, 2016). However, of higher relevance to this study is the migration of Chinese workers and their families (over 200,000 between the 1960's and 1997) occurred during the British government in Hong Kong (Chan et al., 1997), representing a significant group of those residing in England. In addition, since around the year 2000 there was evidence of large and steady periods of migration that included students and economic migrants from mainland China (Shen, 2005).

Latest census data from England and Wales

The estimated number of self-reported Chinese residents in England and Wales in the 2011 national census was nearly 300,000 born abroad and 93,000 UK born, comprising 0.7% of the population. Among the non-UK born, there was a distinct pattern of migration with significant increase in arrival in the 4 years before 2011. The census data described that Chinese migrants originated in different periods, a significant proportion had lived in the country decades, but the latest increase was driven by young adults coming as students. The census analysis reported that 17.7% of residents arrived before 1981, 22.7% arrived in the 20 years between 1981 and 2000, 21% arrived in the 5 years between 2001 and 2006, and a majority of 38.6% arrived in the 4 years between 2007 and 2011, (Office for National Statistics, 2015). These patterns also coincided with a significant increase in referrals to hepatitis services in Sheffield since 2006; Chinese was the largest group comprising 16% of the cohort in 2008 (Smith et al., 2011).

To explore how barriers of access to health care operate in these groups, published evidence of disparities affecting Chinese populations for general health and other conditions in the UK is discussed next.

1.2.2. Access to health care for populations of Chinese ethnicity in the UK

The 2004 Health Survey for England provided up-to-date detailed insight into minority groups' health and compared them with general population health. This helped identifying health needs in regards to common causes of ill health such as cardiovascular disease, diabetes, obesity, and smoking and alcohol consumption. The groups identified as Chinese reported overall better health both in men and women, lower incidence of these conditions, lower systolic blood pressure, lower smoking and alcohol consumption and higher exercise levels than other minority groups and the white population (NHS Health and Social Care Information Centre, 2005).

Infectious diseases where not included in this report, although, as previously discussed, the prevalence of hepatitis B is high in many minority groups. The relevance of studying the case of people of Chinese ethnicity is two fold. Firstly, the high rate of chronic hepatitis B indicates a higher need than for the general population as discussed in section 1.1.1. Secondly, many studies have highlighted reduced access to health care services by Chinese populations in England; this is discussed next.

Evidence of access to health care services in England

Although the health survey described better cardiovascular health, lower diabetes incidence and stroke risk factors for people identified as Chinese (NHS Health and Social Care Information Centre, 2005), there was evidence that access to healthcare for many conditions is low in comparison to other ethnically defined groups and the wider British population as discussed next.

Barriers attributed to discordant language were described in other studies carried out in England. A study in the 1990's found that the health of Chinese in London was comparable to that of the average general English population and better than other ethnic groups (in areas of cardiovascular disease and diabetes). However, the use of health care services was lower than expected both in relation to their level of health and in comparison to other ethnic groups. The strongest predictor of use of health services was the ability to communicate in English (Sproston et al., 2001). When the study was conducted, there was no clear UK policy encouraging the use of interpreters in the national services, although it was a recognizable need (Jones et al., 1998). The collection of ethnic categories and the provision of interpreters was highlighted as a requirement to address institutional racism (Department of Health, 2001). This measure was established after the Race Relation Act Amendment in 2000 stated that it is unlawful for any public authority to exert racial discrimination and that it is their responsibility to take positive action to prevent unwitting discrimination (UK Parliament, 2000). The availability of language support is now widespread within health and social care services (Race Equality Foundation et al., 2013). As discordant language was highlighted in these earlier studies, it would be logical to argue that improving language support may have improved access for Chinese and other populations (Karliner et al., 2007). However, studies continue to highlight disparities that affect this and other populations accessing health care services in the context of having support for discordant language.

A recent qualitative study explored the use of health services and of complementary medicine by Chinese residents in London using six focus groups involving 48 participants. Rochelle et al. (2010) highlighted the lack of knowledge of available services and concomitant language difficulties. Participants described they found difficulties in explaining their symptoms to their providers, that supportive information was of no use if written in English and that they wanted to have more continuity of care which Traditional Chinese Medicine provided. In addition, there was distrust that interpreters correctly communicated their needs. The study concludes that: "*the National Health Service was considered to be difficult to use, and concerns included the language barrier and being able to trust health providers*" (Rochelle et al., 2010).

Lack of confidence in the NHS was found in a third of respondents in the North of England in a cross sectional study looking at awareness and attendance to cancer-screening-programs by Chinese populations (Conway et al., 2014). Although self-reported use of GP services and satisfaction in the study was high, only 57% of eligible women reported awareness of cervical cancer screening programmes, a mere 20% reported awareness of human papilloma virus (HPV) vaccine and an understanding of what preventive programs provide had not been achieved. The low awareness of cancer screening programs was marked in individuals reporting that their English was poor.

Accessing cancer screening and treatment services by Chinese people in London (Papadopoulos et al., 2007), and fall-prevention services for the elderly including 30 Chinese people (Dickinson et al., 2011) were found to be affected by poor communication from health providers, language discordance between providers and individuals and by health promotion failing to be culturally adequate.

Clarke et al. (2013) concluded that measures such as collecting data and providing interpreters had limited effect in reducing disparities in health care access to services. Other factors such as institutional norms and service structure contributed in sustaining such inequalities. Addressing individual factors in isolation, whether from service users, wider population or even from individuals working in a health service ignores the influence wider structural societal factors have on health care access (Metzl et al., 2014). In a study in England examining commissioning organizations, equity in health care based in the concept of race was marginalized and guidance was unclear in the complexity of UK health systems (Salway et al., 2016). Salway et al. (2016) study concluded that local service structures are influenced by long standing unsupportive organizational rules and processes; these in turn being impacted by healthcare policy poorly aligned with ethnic equity developed in a particular socio-political context that has an ambivalent agenda for racial equity. The concept of systemic racism at a societal level influencing institutional norms and practices has been an important framework to understand inequalities (Golash-Boza, 2016; Nazroo et al., 2020); the next section on models of access examines this further.

The studies described above identified barriers in accessing primary and secondary care by Chinese residents for prevalent health conditions in England such as cancer screening, cancer treatment, prevention of falls and general health services. For this study, questions remain about the main factors influencing access for a silent infection of low prevalence in England, such as chronic hepatitis B and this is explored next.

1.2.3. Access to health care for chronic hepatitis B in Chinese populations

Earlier in this Chapter, patterns of migration of people from China were described, the more recent migration episodes, especially those happening during the last 60 years, are of relevance to this study. Increased migration could potentially influence awareness of certain conditions of less significance in the UK such as chronic hepatitis B with a resulting adjustment of services in pursuit of addressing such needs (Gushulak et al., 2006). For example, the increasing number of referrals to our local service from 2004 to 2008 for chronic hepatitis B, resulted in the development of a specialised out-patient based clinical provision (Smith et al., 2011). The increase in referrals included a majority of people from East Asia especially from China. An increase in the numbers of migrants from a different population with high prevalence of chronic hepatitis B, triggered the development of a local enhanced programme of testing and referral to specialists in Sheffield (Gregory et al., 2014). This programme helped tackle one population with a particular need that had recently migrated locally. In relation to Chinese populations, a city-wide surveillance data study in Bristol, England, showed that of 6,248 eligible residents born in China or Hong-Kong and registered with a GP, only 337 (5%) had been tested for hepatitis B by 2015 (Evlampidou et al., 2016). This gap in testing occurred despite the release of guidance for testing people at risk of infection with viral hepatitis in 2012, but considered also testing at any time before 2012 (National Institute for Health and Clinical Excellence, 2012). In addition, results of community based projects of migrants of Chinese origin offering tests for viral hepatitis in Newcastle (Mcpherson et al., 2013) and in Sheffield (Vedio et al., 2013), showed disparities in access to services. Two in three people affected were unaware of having chronic hepatitis B, pointing to a high proportion of people not accessing early diagnostic tests. A further area of concern is that one third of people testing positive were previously aware of their infection, but a majority of them (60 to 80%) were not accessing health care services in the two studies in England and in one additional study in Holland (Veldhuijzen et al., 2012; Mcpherson et al., 2013; Vedio et al., 2013).

In relation to this gap, it is useful to examine the worldwide evidence available in regards to access to health care services for chronic hepatitis B and this is discussed next.

Barriers affecting Chinese populations access for chronic hepatitis B treatment

As part of the wider study a mixed methods systematic review was carried out, this confirmed that the majority of studies are based in North America, especially in USA, with only one study based in the UK. The review assessed the evidence using a modified set of statements based on a previous study (McLean et al., 2014). The statements indicated whether the evidence was a. strong (quality and evidence), weak (quality and evidence) or indicative (one strong study), and b. whether it was consistent (coherent results), equivocal (contrasting results) or confounded (study not designed to isolate factor of interest).

The systematic synthesis showed that there is strong consistent evidence of low knowledge and awareness in Chinese residents and the importance of the infection may not be realized (Thompson et al., 2003; Ma et al., 2006; Coronado et al., 2007). There was also strong consistent evidence of low engagement and poor satisfaction with health care services in relation with chronic hepatitis B (Chang et al., 2008; Chen et al., 2010; Tokes et al., 2014; Sweeney et al., 2015). The study showed that weak but consistent evidence of stigma against chronic hepatitis B exists that may prevent individuals from requesting testing (Li et al., 2010; Cotler et al., 2012). However, evidence of how these factors work as barriers to access to health care is not clear. Intervention studies were not designed to isolate these factors therefore their effect on access to health care is confounded (Taylor, Hislop, et al., 2009; Bailey et al., 2011; Chao et al., 2011; Taylor et al., 2011, 2013; Trinh-Shevrin et al., 2011; Pollack et al., 2011; Ma et al., 2012). In addition, most intervention studies targeted population driven factors through awareness and education campaigns or programmes (McPhee et al., 2003; Chao et al., 2009; Taylor, Teh, et al., 2009; Taylor et al., 2011; Juon et al., 2014), and community lay workers and encouraging linkage to hepatitis services (Taylor, Hislop, et al., 2009; Chen et al., 2013; Taylor et al., 2013). One single successful intervention study clearly addressed practitioner factors, which is discussed in the next Chapter (Hsu et al., 2013); and two studies provided both education to communities and affordable access to local hepatitis services (Bailey et al., 2011; Pollack et al., 2011). However, none of the studies addressed policy and wider structural health system factors that could permit successful programs to continue.

Overall, the review highlighted multiple and layered factors that may act as barriers for access to health care services for chronic hepatitis B in this population. But an important conclusion of this review was that the studies mostly focused on exploring or addressing population barriers with little emphasis on health system barriers (Vedio et al., 2017). Studying only population barriers and inadequately examining system barriers is unlikely to be sufficient, and operatively overlooks the need for changes required in the health care system (Clarke et al., 2013; Metzl et al., 2014). The focus on population or individual barriers is a strategy used over the last thirty years to address disparities in health and thorough review of system barriers to improving access by underserved minorities have been largely ignored (Clarke et al., 2013).

In order to help assessing factors contributing to poor access to health care that originate in health services and health practitioners the next section explores different access to health care models and other models useful for exploring practitioner and clinical encounter related factors.

1.3. Access to health care services

Access to health care involves complex and dynamic processes of interaction between individuals and services. The purpose of accessing health care is to obtain appropriate and timely health care; health services functions should enable opportune access to address health care needs including those of chronic subclinical conditions (Levesque et al., 2013).

In vulnerable groups including migrants, achieving equitable health care access continues to be a problem that concerns health services and policy makers (Zimmerman et al., 2011). It is important to mention here that inequalities in health are closely related to the concept of access to health care services and understanding this relation helps to frame the role of services and practitioners. For example, the European report of the World Health Organization, addressing inequalities in health, concludes that the concept is concerned with factors that are systematic, avoidable and unfair. It implies that services and professionals should strive to deliver services that respond to differences in health care needs. The discussion about the role of health care services states: *"The end goal of 'equity in health care' would be to closely match services to the level of need, which may very well result in large differences in access and use of services between different socioeconomic groups, favouring the more disadvantaged groups in greatest need"* (Whitehead et al., 2007).

The concept and study of access to health care hence needs to acknowledge factors inherent to health care services and national strategy, identifying inequities embedded in the system, and how can these can be addressed. It is useful to understand that systemic and structural racism (Nazroo et al., 2020) and structural stigma (Metzl et al., 2014) play a role in health inequalities and is important to look at these in the context of this study and in relation to models of access to health care.

Introduction to theoretical models of access

This study draws on models of access that explore barriers pertinent to service provision. The focus is in exploring health service practice, with practitioners and their experience of interactions with patients at the centre of the enquiry. My intention is to build a picture of the factors related to practitioners that may facilitate or hinder access for migrant Chinese for chronic hepatitis B. The ultimate aim is to identify what factors could be improved or challenged from a health care service perspective with the vision of improving health care access. Exploration of known access to health care models helped identifying those that acknowledge the functions related to the role of health care practitioners and of health services.

1.3.1. Access to health care models

The definition of access to health care has been discussed for many decades in different forums and has evolved overtime from partial views of utilization of existent health services to ones that understand dynamic interactions between individuals, support systems and services (Ricketts et al., 2005). Numerous "access to health care" models are found in the literature that have been used by economists, policy makers or technology assessors for example; but the definition of access and what is included in the models continues to change (Levesque et al., 2013). While examining frequently used models such as the original Andersen's model (1968) and its many iterations, it was clear that these models focus on the steps leading to access that are dependent on individual and on social characteristics affecting health behaviour (health literacy, family and social support). Modifications to improve the model focused on self-reported outcome of the interaction, such as perceived health and user satisfaction, as a reflection of service efficacy (Aday et al., 1974; Andersen et al., 1983; Andersen, 1995; Gelberg et al., 2000). In these models, services appear static and their functions or the interaction between user and system are scarcely explored. It is possible to consider the domain of satisfaction as a partial surrogate of such interaction, but this does not provide any information about the particular factors pertinent to services that may shape access. Other authors recognised this lack and discussed the need to incorporate the roles of services in the process; for example, the "FIT" model raised the need to provide services that respond to the needs of the populations accessing them. The model include needs, demand and consumer satisfaction as domains (Penchansky et al., 1981).

Another important contribution is the use of the term accessibility as a function and capability exclusive to services indicating there can be organizational obstacles to the process. First published in Spanish in 1985 by the World Health Organization (WHO) and later translated into English, the publication aimed to stratify and identify the narrow concept that establishes accessibility as the ability of services to respond effectively to population's health needs (Frenk, 1992). These three major theoretical models: Aday & Andersen's 1995 model of access, Penchansky's FIT model and Frenk's domains of access were reviewed to explore how they addressed the responsibility of systems to tackle barriers appearing to be population based (Ricketts et al., 2005). The review highlighted the impact of the interaction with services can have in the process of access; and how the interactions can influence effective health seeking by deterring individuals from presenting again when a previous negative experience occurred. This is a phenomenon studied in access to mental health services, that has been conceptualized as recursivity (Kovandžić et al., 2011). In a similar fashion to the recursivity concept, Ricketts' study underlined the need to define competencies of the health care systems that could have a negative impact in people's behaviour, confidence and trust and encourages more dynamic models to be considered that would take in account these factors in order to influence policy and practice. The authors discuss the difficulty in evaluating acceptability and accessibility of services because of the complexity of factors affecting health care seeking and receiving, and the difficulty in qualifying the influence of experiences with services. The review also acknowledged that health care systems are ever-changing environments that respond to multiple organizational and societal factors and these need to be considered when exploring access.

More recently Levesque, et al. (2013) synthetized eleven models of access to health care with particular emphasis in defining and developing a conceptual framework. The paper describes five dimensions of accessibility (approachability, acceptability, availability/accommodation, affordability, and appropriateness) as qualities of services using features related to organizational supply for population demand. These five domains reflect five abilities accorded to persons interacting with services (ability to: perceive, seek, reach, pay and engage), interaction being the operative word in this conceptual framework (all domains and interactions are described in Appendix 1.3). These important aspects can guide identifying and discussing organizational factors that contribute to the barriers in access to health care services for underserved populations. Practitioners' functions in this comprehensive synthesis appear distributed around acceptability where cultural and social factors may influence access, and around appropriateness highlighting timeliness and correct skills for health care provision.

When searching for models that could describe more specific functions to health practitioners' practice, and that can help identify barriers for disadvantaged groups, it was noticeable that defining characteristics of practitioners' roles in the process was not frequently addressed. However, while developing a generalizable and more practical model that can explore access for vulnerable populations, Dixon-Woods (2006) generated the "candidacy model". The model was derived from a critical interpretive review of the literature and incorporates both the process of recognition of need for care by individuals, and the active role of health practitioners when assessing health needs of individuals and when offering care. The candidacy model outlines domains in the access pathway and identifies “functions” of practitioners in the interaction (Dixon-Woods et al., 2006). It presents a platform for exploring factors affecting these functions; therefore, I explore this model next as contributing to provide an overall frame for this study.

1.3.2. Candidacy model (Dixon-Woods et al., 2005)

Identification of candidacy, adjudication, and offer of services

The candidacy model establishes separate domains that related to individuals, health care practitioners and interactions with services as shown in Table 1.3-1

Table 1.3 - Domains of the Candidacy model

Domains pertinent to individuals	Identification of candidacy Appearance at services Resistance to offer
Domains pertinent to health care practitioners	Adjudication of candidacy Offer of service
Domains pertinent to interaction between individual and services	Navigation (individual centered) Permeability of services (service or system centered)

The initial domain that appears in the Dixon-Woods' model is called "identification of candidacy". This is described as the process of how people recognize that their symptoms or concerns deserve medical attention. Identifying candidacy has many modifying factors that can act as facilitators or deterrents and these can be based on prior experiences with services, health beliefs and social background and support as shown in Figure 1.3-1. Identification of candidacy may or may not be followed by navigation and appearance at health services. Since "identification of candidacy" is a domain that is not directly related to services or practitioners, I briefly discuss it here in relation to chronic hepatitis B.

In chronic hepatitis B, symptoms will not trigger seeking medical attention unless there is a serious complication and this will imply late or advanced disease. It is important to know that the aim of providing early diagnosis and treatment is to prevent complications from occurring. Applying the candidacy model to chronic hepatitis B where individuals are unlikely to present with symptoms early in the disease reflects a different pathway in access. It indicates that practitioners are key in identifying the need for diagnosis. It is possible that individuals will identify the need for diagnosis if they are aware of having an increased risk for chronic hepatitis B. This may be due to awareness of high prevalence in their country or having friends or relatives affected by it. But multiple social and economic priorities and factors may influence the process and act as barriers (Lee et al., 2017). Understanding the role that practitioners and services play in overcoming barriers is key to this study.

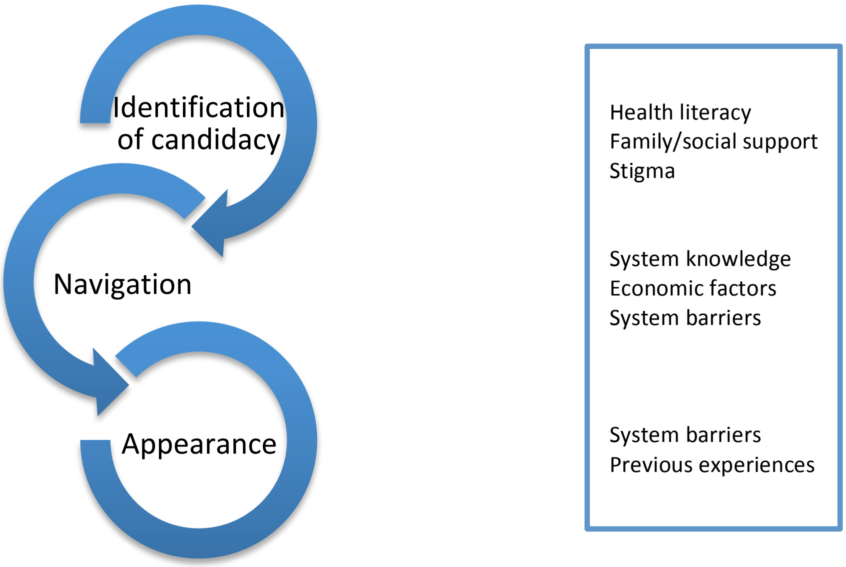

Figure 1.3.1 – Graphic representation of identification of candidacy, navigation and appearance and related factors described by Dixon-Woods (2005).

The emphasis of this study rests in the domains pertinent to health practitioners called “adjudication” and “offer”. The candidacy domains of “adjudication” and “offer” are functions that can be exercised during opportunistic risk assessment for chronic hepatitis B, as advised by UK guidelines (National Institute for Health and Clinical Excellence, 2012). Opportunistic risk assessment means that the service or practitioner initiates the pathway when individuals attend for other reasons. Ideally, practitioners evaluate the likelihood of having chronic hepatitis B infection or consider a patient’s request for a test and discuss whether the request is reasonable and testing is clinically indicated. The function of “adjudication” can be moderated by good clinical skills and appropriate knowledge of the condition, although national or local policy and protocols are expected to influence the action taken. If the practitioner “adjudicates” candidacy, the next function is to “offer” services. For example, offering a test for hepatitis B to people who are considered to be at risk, offering immunization to those who are susceptible, or offer of referral to appropriate services for evaluation and treatment if chronic hepatitis B is diagnosed as it is practice in the UK, are ideal practice pathways for this domain.

In summary, a practitioner must evaluate the risk of viral hepatitis and offer information and testing to the individual. Practitioners offer testing prompted by local or national guidelines, or by evaluating the risk of infection if mindful of the need for early diagnosis, knowledge of close contacts with the condition or awareness of other risk factors. The individual, based on own preferences, concerns and awareness may accept or decline the offer. In a similar scenario, assessing contacts of patients with HBV may lead to the “offer” of immunization to close contacts that are still susceptible to acquiring the infection.

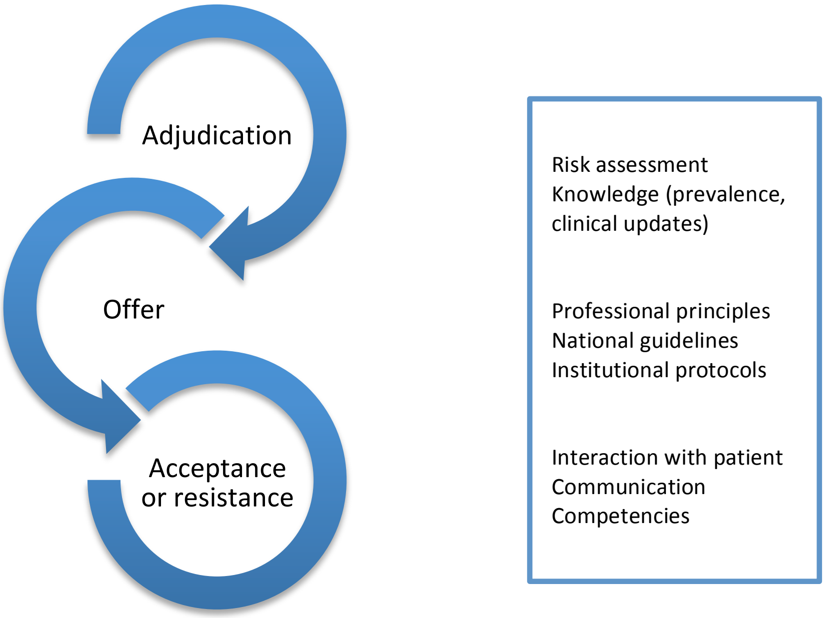

Figure 1.3.2 - Graphic representation of domains described by Dixon-Woods (2006) related to the practitioners and potential relevant factors

The model describes there is agency in resistance (or acceptance) to offer of services, which is a domain of individuals seeking care. The model, in this way, places the practitioner as dominating the process of decision-making. This is addressed in a later section by incorporating concepts that support and expand the candidacy model.

Although the central interaction of individuals with services is the encounter with health practitioners, many other interactions mediate access. This study does not examine interactions with administrative or other workers involved in clinical settings; the focus is on practitioners and therefore restricted to the main clinical encounter. But it is necessary to acknowledge that these mediating interactions can greatly influence access at different stages of navigation; therefore influencing access to services (Arber et al., 1985; Neuwelt et al., 2015). In addition, organizational issues may be important barriers affecting navigation and appearance. These barriers are considered within the candidacy model via the incorporation of the idea of permeability and ease of access, and this is discussed next.

Candidacy model: navigation and permeability of services

A viewpoint that characterises the candidacy model is that accessing services can be a difficult endeavour for vulnerable populations, acknowledging that it requires complex skills to navigate hurdles inherent to a system built with multiple structural barriers. Non-familiarity with such system and unfavourable encounters could add to other barriers with the unintended consequence of restricting access to services. In the candidacy model, services are characterised by their “permeability”, in other words the complexity of requirements for access to such service (Dixon-Woods et al., 2005). A highly permeable service can be accessed without the need for overcoming many hurdles; good examples of highly permeable services are emergency departments and, in the UK, primary care walk-in services. The structural complexity of systems acting as barriers and the familiarity required to overcome obstacles are usually characteristic of the local (regional or national) system, which may differ significantly from systems in other countries (Dixon-Woods, 2005; Dixon-Woods et al., 2006).

In the case of chronic hepatitis B, a silent disease, an ideal pathway would allow individuals to access testing despite the lack of symptoms or signs of hepatitis. As discussed in the previous section, individuals could access the step of testing if they request it from their General Practitioner. If the condition is diagnosed, a pathway of care could then take place. In England, where this study is conducted, the condition is looked after by specialized secondary services (National Institute for Health and Clinical Excellence, 2017). These services can only be accessed through referral by primary care or other services (sexual health, antenatal and other secondary health care services) and therefore have “low permeability”, as individuals are not able to access hepatitis services voluntarily, but only through the mediation of other services. Some exceptions to the pathway for testing and referral, can bypass interactions with a GP. Individuals can self-refer to sexual health services where testing for hepatitis B is part of infection screening for people or partners of people born in countries of high or intermediate prevalence, and this is also followed by referral to specialist services if the infection is present (BASHH, 2015). In antenatal services, hepatitis B is one of the tests offered for preventive management of perinatal transmission; prompt referral to hepatitis services and review within six weeks of referral has been incorporated into the pregnancy management protocols (Public Health England, 2017).

Primary and secondary care practitioners, as gatekeepers of access, need to be alert to clinical and epidemiological risks and offer testing, and then offer and provide referral to hepatitis specialists when a diagnosis is made. This process makes the pathway dependent on practitioners’ insight and motivation for testing and referral, and dependent on support or guidance available from the practitioners’ institution for this to happen.

The candidacy model as framework for the study

The construct developed by Dixon-Woods et al. (2005, 2006) helped to delineate the concept that in accessing health care there are multiple pathways of iterative interactions between ever-changing health services and individuals. A useful concept in the model is the recognition that services are not static; these continuously evolve, re-define their aims and reformulate the appropriateness of interventions in the process of responding to health care demands and constraints. Increasing demands may prompt services to adapt by either changing their structure or prioritising certain services over others. For example, the availability of effective treatments for chronic hepatitis B that improve health and prevent complications may prompt a drive in services to achieve early diagnosis and treatment. However, priorities of primary care services may be defined by conditions that have higher prevalence in all populations and for which there are policies and health improvement targets. For example, testing for cardiovascular disease or diabetes will take priority over testing for other less pressing conditions applicable only to discrete parts of the population such as chronic hepatitis B. In this way, populations where chronic hepatitis B causes significant morbidity and early mortality may not access health care if testing and prevention services are not being offered and this particular health need is not addressed.

Barriers emerging from services in the interaction with the population in need of care for chronic hepatitis B require exploration. In addition to exploring practitioner centered models, I investigated structural, institutional and interpersonal racism concepts to help establish a base for discussion about the interweaving effect racism can exert on all these processes (Nazroo et al., 2020). The theories are discussed within the next section.

1.3.3. Concepts that complement the candidacy model

The candidacy model aimed to provide an understanding of the interactive and dynamic path involved in accessing care by vulnerable groups (Dixon-Woods et al., 2005). However, there are areas relevant to the clinical encounter and to cross-cultural care that are not sufficiently explored in the model and for this I draw from shared-decision making models and also models that address cross-cultural care issues relevant to the work of health care practitioners.

Shared decision-making

The clinical encounter is characterized by an exchange of information and of priorities and values that inform the process of clinical decision-making. The shared decision-making model is characterized by a bidirectional exchange of information and deliberation between individuals and professionals with a view to achieve a decision not only related to a medical condition but also taking in account patients' values, priorities and expectations (Murray et al., 2006). Recognition of practitioner and individual cultural influences and expectations affecting decision-making in the clinical encounter is part of this model, in particular of assumptions of how the process should be, as this may not be shared by individuals with different cultural background (Charles et al., 2006).

The clinical encounter is considered to have an intrinsic imbalance of power; the concept of power has been examined from the point of view of knowledge owning (Joseph-Williams, Elwyn, et al., 2014). This imbalance is addressed by seeking deliberation, negotiation and integration of patient's values and preferences (Makoul et al., 2006). Health professionals hold considerable power to make decisions based on the concept of ‘owner of knowledge’; this is the base of the older paternalistic decision-making model (Charles et al., 1999). The development of numerous alternatives for treatment of conditions such as cancer, combined with widespread access to medical information, meant the interaction evolved into a model where patients are directly involved in decision-making and this has shown to be beneficial to outcomes (Elwyn et al., 2014). Makoul et al. (2006) integrated definitions from shared decision models in health care and defined elements essential to the process. For example, the process includes the need to provide information about all options, and the need to check understanding and ability to make an informed decision. In addition, the qualities of the process of shared decision-making were deliberation, mutual respect and patient participation among others. These concepts amplify the roles described in the candidacy model by qualifying the ways in which adjudication and offer might take place, and by addressing the uneven distribution of power during the interaction.

Cross-cultural communication

Culture is a widely discussed concept with many connotations in relation to health care. In a health care restricted context, culture is defined by Charles (2006) as *“the expected (socially sanctioned or legitimized) set of roles, attitudes, behaviour and beliefs of health care providers and patients about health and health care in general and treatment decision-making in particular”*. Although there are many other definitions, discussion of these goes beyond the aim of this chapter. In a particular culture, values, perspectives and ideas are shared through learning and socialization. But cultures are not homogenous, and understanding of cross-cultural differences need to allow for diversity within cultures (Holloway et al., 2010). The definition of culture in regards to health care helps to set in context the complexity involved in exchanging information between patients and practitioners. Cultural discordance and misunderstandings in communication that are not managed well by the professional may influence the delivery and receipt of health care services (George, 2017). Cross-cultural communication skills and addressing cultural dissonance (or the discomfort or conflict experienced by individuals due to cultural differences that could affect communication) can help practitioners balancing power dynamics during candidacy adjudication and offer of services (Dixon-Woods et al., 2005). Ensuring that deliberation and exploration of doubts or discomfort happen during an offer of testing for hepatitis B, could clarify factors unknown to the practitioner such as stigma or previous experiences with serious illness in family or friends. Individuals may chose not to be tested or decline an offer to be referred to specialists for many different reasons and this will need careful exploration. In a paternalistic model of consultation, this process of acknowledgment and exploration is unlikely to happen when discomfort and uncertainty are present (Charles et al., 2006; Kai et al., 2007).

Chronic hepatitis B, like other asymptomatic conditions, could be best addressed when patients present for other reasons. This can be achieved by practitioners checking for known risk factors as delineated in national guidelines (National Institute for Health and Clinical Excellence, 2012). The decision to offer a test would be a constructed evaluation of the patient's health benefit and a deliberation between practitioner and patient about preferences and values that may affect the individual's choice. An individual's preference to not be tested may represent a response to hepatitis B associated stigma or be based on knowledge about the disease or the health care process (Lee et al., 2017). Multiple encounters in the pathway could influence the process of accessing appropriate health care. If the offer is accepted and test results show that the individual is affected by chronic hepatitis B, referral to a specialist service requires further deliberation and it implies new clinical encounters and new deliberations between a practitioner and the individual. Once the contact with specialist hepatitis services occurred, and if treatment is needed, there may be factors that affect the process of access to treatment in the multiple health care encounters conceptualised by Dixon-Woods (2006), which include earlier experiences with services acting as facilitators or deterrents. The process of adjudication requires the recognition that chronic hepatitis B is prevalent and may affect health long term. In addition, it requires an understanding of factors affecting spoken communication in shared decision-making during offer of services, and the impact of systemic factors (Papatheodoridis et al., 2016).

In relation to the factors explained above, the information provided by practitioners would need to include an explanation of the likelihood of having the infection in a non-stigmatising way. The practitioner would need to balance the benefits of early diagnosis for the individual and assess how this concurs with the individual's values and preferences (Mulley et al., 2012). Experience of stigma or discrimination, and having correct information about the condition and about the personal impact of a positive diagnosis may influence preferences in undergoing testing for hepatitis B (Wallace et al., 2011; Lee et al., 2017). These considerations may be influenced by the practitioner's understanding of how cultural differences, particularly how dominant culture expectations or assumptions, may affect the power balance within the clinical encounter (Jirwe et al., 2009; Foronda et al., 2015). Factors such as dominant cultural biases and structural racism may influence this assumptions and be detrimental to understanding individual's values and preferences (Charles et al., 2010; Mulley et al., 2012). In order to explore potential barriers arising from practitioners in cross-cultural encounters cultural competence, sensitivity and humility models are discussed next.

Cultural competence, sensitivity and humility

For this study is important to draw on the competencies that may influence health encounters across cultures. There is abundant literature around the question of how to best frame competencies and I will briefly mention the main issues. Cultural competence is widely cited and used as a base for training of health care practitioners. However, this concept is not well defined and contested as resulting in partial understanding of barriers, stereotyping and negation of wider system influence (Drevdahl et al., 2008; George et al., 2015). In advancing the discussion about how to improve delivery of appropriate health care, important concepts include the awareness of, and the relationship practitioners have with their own culture, with understanding of their own limitations, and with developing flexibility in order to achieve effective communication during the decision-making process. I draw these concepts from a wide evidence review and consensus statement carried out in Sweden (Jirwe et al., 2009). The review synthesised a number of current cultural competence models and established a consensus of what is important for application in practice. It identified cultural sensitivity as the bases of good transcultural care. Cultural sensitivity has two main components, the practitioner's attributes of "*compassion, empathy, respect, flexibility and openness towards differences"*; and the practitioner's insight into their *"own prejudices and stereotypical attitudes, and of their own cultural identity".* Jirwe et al (2009) argue that if these attributes are lacking, other components of such as awareness of transcultural encounters, communication skills, and diversity awareness (of gender dynamics, religion, educational and economic background) among other, can easily fail to support an effective and equitable health care encounter.

> *"In this regard, nurses [practitioners] need to develop an understanding of their own cultural identity, stereotypical assumptions and potential ethnocentrism to adopt a non judgmental approach in their interactions with people from a different culture to their own" (Jirwe et al., 2009).*

Cultural sensitivity implies understanding of own cultural identity and assumptions, (includes 11 statements) and personal attributes (includes 12 statements) that reached consensus using a Delphi technique (Jirwe et al., 2009). The full list of statements is included in Appendix 1, Table A1.4. The statements described imply a process of personal development and self-reflection. The model does not explain how to achieve these conditions and how to identify if these conditions are being met. To complement this model, the concept of cultural humility adds conditions that guide self-reflection and describes the process as life-long learning using a process of continuous self-evaluation of own biases and assumptions (Tervalon et al., 1998). A recent review of cultural humility models addresses the background of power imbalance and understanding diversity by specifying attributes of *“openness, self-awareness, egoless, supportive interactions, and self-reflection and critique”* (Foronda et al., 2014). It adds to the previous discussed work in that highlights the interactions and understanding of all participants in the clinical encounter and includes interactions between practitioners of different professions within the system. It aims to build on a concept of workplace flattened hierarchy and mutual empowerment and helps to expand on the practical issues of cultural sensitivity in clinical practice. Although this is not strictly confined to the clinical encounter, the development of a culture of humility in the work place supports the development of cultural humility in the clinical encounter, and brings to practice the concept of institutional commitment to eliminate racial inequalities in health care (George et al., 2015).

Influence of organizational culture

Clinical encounters happen in an institutional or organizational context that regulates and influences practice. Why do we need to examine organizational culture? When looking at understanding racial inequalities in severe mental health illness Nazroo et al. (2020), found that the interaction between interpersonal, structural and institutional racism continued to drive discrimination and inequalities. In a study of healthcare commissioning processes acting as barriers to race equity, marginalization of the agenda, ambivalence about the existence of ethnic inequalities and lack of clarity of how commissioning bodies contributed to this inequality were found as factors limiting policy and funding of programmes supporting equity in health care (Salway et al., 2016).

Expanding from a concept of individual practitioner qualities to one of organizational competencies is essential to understand the support available for practitioners' roles in the accessing of health care services by underserved populations (Metzl et al., 2014). For example, in the concept of structural stigma, there needs to be awareness that social conditions, cultural norms, and institutional policies might constrain the already limited opportunities and resources of the populations we are intending to address and that may be already stigmatized (Hatzenbuehler et al., 2014).

The concept of structural racism proposes that despite efforts to eliminate interactional racism, many of the barriers persist due to an established set of structures based on a dominant culture that pays little attention to the needs of non-dominant ethnic groups (McKenzie, 2003; Drevdahl et al., 2008). Barriers to access to health care that are organizational can be examined from a point of view of services structure and responsibilities. Levesque (2013) deconstructs services accessibility, by describing conditions of providers, organizations, institutions and systems that enhance the possibility of access and allows examination in more detail (described in the previous section). Although the candidacy model was not included in the synthesis by Levesque, the elements of service qualities and responsibilities allowed a more meticulous examination of factors associated with health services and helped to inform the analysis and discussion for this study of practitioners. It establishes characteristics and responsibilities of services that serve as platforms for improving interaction with services by users. For example, the ability of users to seek, reach and engage with services is supported or hindered by geographical location, appointment mechanisms, quality of interpersonal communication, coordination and continuity of services (Dixon-Woods et al., 2005; Levesque et al., 2013). In addition, making services efficient in relation to the broader determinants of health and addressing structural discrimination, stigma or racism, may require intervening and innovating beyond the walls of organizations (Drevdahl et al., 2008). These contextual factors may determine some factors pertinent to roles and responsibilities of practitioners. Definitions of racism concepts that contributed to the analysis, and were applied to the interpretation of data in this study, are included in Table 1-1.

Table 1-1 Concepts on racism in health from the literature that contributed to interpretation of results

Author / Reference	**Concepts**	**Application to this enquiry**
(Drevdahl et al., 2008)	"creation of difference from dominant culture, language of difference" "critical thinking, reflective practice, political action"	Does the data demonstrate a dominant language of difference? Does it demonstrate critical and reflective thinking?
(Salway et al., 2016)	"marginalization of racial equity agenda" "ambivalence and resistance to acknowledging inequities" "lack of clarity, lack of confidence in addressing inequities"	Is there evidence of marginalization, ambivalence and lack of clarity in practice or in factors identified from participants' narratives?
(Nazroo et al., 2020)	"institutions reproduce and are shaped by structural* and interpersonal** racialization§ and racism"	Is there evidence of institutional barriers that shape practices at interpersonal level?

Definitions according to Nazroo et al. (2020)

* Structural racism: wider, at macro-level, social, political, cultural and ideological conditions that influence the development of racist institutions and are interdependent with interpersonal racism.

** Interpersonal racism: interactions where deliberate or unwitting discrimination is present, "every day racism", these are influenced by and contribute to structural racism

§ Racialization: historical and political power constructs attributed to physical / cultural differences that lead to disadvantage of those with racialized identities

Finally, in order to understand individual professional processes involved during practice I examined the behavioural framework developed by Michie et al. (2011).

The behaviour wheel components

Adjudication of candidacy and offer of services as described by Dixon-Woods (2006), consists of reaching a decision within the confines of the time allowed during the clinical encounter. Although models described above tend to cover most of the factors that could be involved, I found that the components of behaviour modification described by Michie et al. (2011) on the Behaviour Wheel, were concise concepts that could help focus the individual practitioner factors complementing the candidacy model. The domains of interest for this study are defined by the three components of COM-B. These are capability (skills and knowledge), opportunity (social and physical) and motivation (reflexive and automatic) and were used mainly to help the breaking up and understanding of data for analysis.

1.3.4. How these models guide the study

Dixon-Woods (2006) candidacy model provides a basic frame for interpretation of the participants' narratives. For chronic hepatitis B, the clinical encounter provides the context for discussion of identification and adjudication of candidacy and offer of services.

The way these are approached can be influenced by the imbalance of power in the encounter as discussed by Charles (2006), understanding the concept of shared decision-making can help identify power conflict in the narratives, and understand whether these are acting as barriers in accessing health care services. The competencies of the professionals in cross-cultural encounters (Jirwe et al., 2009; Foronda et al., 2014) provide a guide to understand if practitioners are experiencing difficulties in these areas and whether these can be significant barriers or can be acting as facilitators to access to health care.

In exploring practitioners' narratives, it may be possible to have insights about institutional cultural norms that are considered factors that influence access. A starting point to exploring structural barriers that can influence accessing services for chronic hepatitis B may include understanding the accessibility of services or permeability domain of the candidacy model described in the previous section. In addition, awareness or insight about historical and structural barriers may be identified in the narratives (Drevdahl et al., 2008; Metzl et al., 2014). Reflexion about these concepts bring us to a conclusion that being aware of structural and historical barriers in a context of interpersonal interaction happening within a background of racial inequalities is necessary to understand in depth the role of services and practitioners in perpetuating such barriers (Drevdahl et al., 2008; Metzl et al., 2014; Nazroo et al., 2020).

In examining individual participant responses in this study the components of behaviour modification (Michie et al., 2011) were used to break the data during indexing for analysis and were helpful to identify individual practitioner factors acting during the clinical encounter.

Although I did not employ all these theories in setting a framework for this study, many of these concepts helped me to understand context and system factors when indexing and interpreting results.

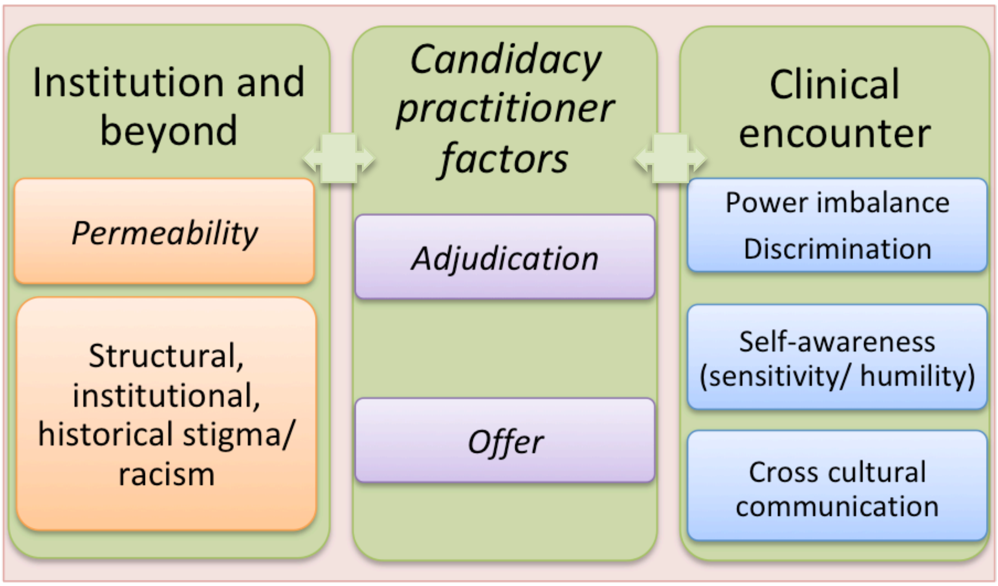

Figure 1-1.3 Summary of different concepts that may relate to the candidacy model domains in relation to practitioners

1.4. Summary

Access to health care is a complex process that can be affected by a multiplicity of factors and this study will focus in the role of practitioners during that process. Early diagnosis of chronic hepatitis B is desirable but there is evidence that access to services by populations at risk is insufficient. Identifying the infection through testing the blood can start the access to health care pathway for chronic hepatitis B. However, following the release of NICE guidelines in 2012 that recommended testing groups at risk and linking them to services, a very low proportion of East Asians in England had been tested in a study by Evlampidou et al. (2016). This is relevant as chronic hepatitis B affects a significant proportion of people of Chinese ethnicity. The low priority of chronic hepatitis B in the UK and the asymptomatic nature of the condition have the potential of increasing inequities in health for people of Chinese ethnicity. As shown in section 2 of this chapter, UK and worldwide studies show reduced access to health care for Chinese populations for chronic hepatitis B and for other medical conditions.

Using the domains of the candidacy model facilitates the assessment of practitioner related barriers affecting the patients’ journey to accessing health care services. Individuals may not realize the importance of the infection or there may be stigma influencing a decision to seek care. Practitioners’ roles in adjudicating candidacy and offering services are key. Power imbalance, addressing decision-making preferences and professional uncertainty around the condition and the needs of patients need exploring. System processes may also contribute to barriers due to low permeability of secondary health services for chronic hepatitis B. Low permeability may be a reflection of the structural and historical barriers and in turn influence the interaction in the clinical encounter, perpetuating existing racial inequities that act as barriers to accessing health care services.

To document current knowledge and inform this study the literature addressing the role of health practitioners’ in facilitating or hindering access to health care for chronic hepatitis B for populations of Chinese ethnicity is discussed in Chapter 2.

2. Literature Review of Practitioner Studies

This chapter contains the review of literature with a focus on practitioners' studies looking at factors affecting access to health care for chronic hepatitis B among populations of Chinese ethnicity. An initial limited literature search revealed that research discussing this problem exists mostly in other developed countries and could provide useful information for this study. This systematic literature review assumed an interpretive approach and was inclusive of mixed methods.

As part of the wider study of barriers mentioned in the introduction, a systematic search was undertaken that included studies addressing different stakeholders such as populations of Chinese ethnicity and health service practitioners, and included interventions addressing barriers acting at different levels (Vedio et al., 2017). The results of the wider search included both studies addressing populations and studies addressing health practitioners. The outputs of the literature review addressing Chinese populations were discussed in Chapter 1, sections 1.2.2 and 1.2.3. For this chapter, I drew only on publications that included health practitioners' studies and synthesised it with a focus on barriers arising within the context of the health service.

2.1. Review methods

The literature review allowed the study to be informed of previous relevant research undertaken and helped refine a focus for the research question (Booth et al., 2016). To ensure wide and broad inclusion of relevant studies the review aimed to be systematic and interpretive. Adopting a systematic and interpretive rather than an aggregative approach aimed to increase depth and breadth of understanding and allowed findings to be corroborated by incorporating and analysing studies using different methods (Heyvaert et al., 2011).

For the purpose of this review, the definition of the terms screening vs. testing needed clarification. Many studies used the word ‘screening’ to mean ‘testing’. In testing for HBV, there is a clear epidemiological risk, and the test done on a blood sample is diagnostic. Screening is a process of identifying people at increased risk using non diagnostic tools (Wilson et al., 1968). Therefore, in this chapter I have replaced the word ‘screening’ used by some of the literature authors with the word testing for more clarity.

2.1.1. Aim and objectives

The aim of this literature review was to elucidate the current knowledge on the role of health care practitioners in influencing access to health care for chronic hepatitis B in persons of Chinese ethnicity in the UK and in other developed countries; and a secondary aim was to identify the factors associated with facilitating or hindering this role.

The objectives for the review included:

- identifying the relevant literature,
- critically appraising and exploring the data, and
- identifying relevant insights to the question of access to health care.

Further objectives were:

- to synthesize findings and
- to discuss its relevance for practice and policy, and
- to define how the review has informed this study.

Structured search, identification and critical assessment of published studies are essential to provide a reproducible pathway to achieve the aims and objectives (Booth et al., 2016) and these are described next.

2.1.2. Systematic search and inclusion criteria

The search and inclusion criteria aimed to address the requirements for the review to be systematic, inclusive and appropriately refined (Alborz et al., 2004; Booth et al., 2016). This section explains the procedure used for searching, selecting sources and publications, defining the eligibility criteria and the quality appraisal.

Search strategy and sources

The search strategy aimed to be inclusive and broad. Discussion with a specialist librarian at the School of Health and Related Research helped support the choice of databases and refine the search strategy. The strategy was designed to extract the maximum number of relevant papers and sources. The search string included terms to identify the population, terms associated with health care access and terms identifying hepatitis B. Including terms referent to the population of interest needed consideration of labels used in different settings; for example, Asian American was found in American studies while Chinese was used in other countries. For the purpose of being inclusive of intervention studies that could be applicable to the wider study systematic review, search terms included other Easter Asian countries with high hepatitis B prevalence. The publications were extracted from both biomedical (Cinhal, Embase, Medline, PsychINFO) and social sciences databases (ASSIA and Web of Science). The databases definitions and the search strategy protocol were those used for the wider study search and these and examples of search string designs are found in Appendix 2.2.

Study selection process

Sifting through any number of studies obtained by an inclusive search strategy requires careful consideration. This was done in iterative stages during the main review and consensus was reached by discussion between the four researchers involved in the literature review (Booth et al., 2016).

The first sifting was performed on titles and/or abstracts. The publications selected included in their title or abstract a focus on hepatitis B, and on populations identified as Chinese and/or of East Asian ethnicity living in Europe, North America, Australia or New Zealand.

The second selection required reading abstracts or full papers to select publications that studied factors influencing access to health care and excluding any purely epidemiological, laboratory focused, clinical management or opinion papers. From the results obtained, studies involving practitioners were identified and included in this review. A limited updated search was done in 2016 to incorporate recent relevant publications that helped inform the discussion. From the output of this search, the studies addressing practitioners were selected. The section that follows explains data extraction and methods for analysis and synthesis.

2.1.3. Quality assessment, richness, research on ethnicity criteria

Studies were included following a criteria of mixed methods synthesis, this decision was made to increase the pool of studies and to include other than qualitative data that could provide relevant information (Grant et al., 2009).

The emphasis of the approach is on qualitative studies, and these are first on sequential analysis, quantitative and intervention publications are integrated later at the analytic and interpretive stage (Heyvaert et al., 2011).

For the wider review, methodological rigour questions were examined using a questionnaire examining methodological characteristics that included ethnicity criteria for research (Mir et al., 2013). I list all the methodological rigour questions used in the main study in Appendix 2.3. The concept of "richness" of data was useful to determine inclusion into the review. Richness did not limit the incorporation of studies considered to have limited information not only due to the small number of studies, but because of their possible contribution to knowledge.

The question asked to assess richness was:

Is this study likely to offer useful insights into the factors operating at health system level that may be relevant to the planned study focus?

The question aimed to identify studies addressing more than single factors affecting access. Once this condition was fulfilled and to ensure no major methodological issues compromised the validity and trustworthiness of the findings, the studies were examined by method.

There was limited applicability of the wider study methodological rigour questions (Appendix A2.3) to the final list of practitioner studies selected for this review. For the purpose of this thesis, practitioner studies were selected and assessed using quality assessment by methodology. The criteria were generated after review of established criteria and discussion with experts to ensure relevant qualities were assessed. The process of assessment is described in this section and the results can be found in section 2.2.

Qualitative methods assessment:

In order to assess qualitative publications I explored different criteria and concepts of qualitative research quality assessments. A UK report on quality in qualitative evaluation refers to the need to address particular areas to appraise qualitative studies (Spencer et al., 2004). The report systematically synthesised research literature, research methods used in government funded studies, review of existing frameworks and used individual interviews with government participants and academics. The criteria reported by Spencer et al. (2004) included assessment of research design, research practice, research team and documentation; also included congruency of methods and outputs. After review of these and discussion with the supervision team a simplified list of questions was agreed. The assessment for this review aimed to consider potential quality issues, but not to exclude studies that can still provide useful data and raise avenues for exploration. By doing this trustworthiness of the findings could be supported.

Questions to answer for qualitative studies aimed to examine how well the process of research was documented in publications and whether insurmountable research bias was detected:

1. Is there an acknowledgement of researcher influence or bias? With this question the issue of awareness of how biases can emerge, whether there were attempts to minimise it and to address it through analysis was examined as suggested in Spencer et al. (2004 p67).
2. Is there congruity between methods and research aims?

With this question the coherence between the aims and methods are expected to be demonstrable in the publication.

3. Is there acknowledgement of study limitations and how these influenced findings?
4. Is there congruity between research questions and the presentation and interpretation of findings?

Congruity in points 2 and 4 addressed research design, practice and congruency of outputs as described by Spencer et al. (2004). The assessment aimed to be as complete as possible within the limitations of the few studies found.

Quantitative methods assessment:

Cross-sectional studies were examined to assess the appropriateness of the design of studies. It was necessary to address that studies in this area were not strictly quantitative studies. The studies used self-administered or self-evaluated assessments using Likert scales that provide a semi-quantitative assessment of the attitudes or behaviours of practitioners. In Likert scales, the answers are provided in a scale of five to six items that span from “strongly agree” to “strongly disagree” or similar variations. The assessment for this category aimed to assess the presence of bias on sampling, instrument used and analysis by adapting the STROBE statement for observational studies (von Elm et al., 2014).

The assessment included the following:

1. Eligibility and recruitment of participants,
2. Authors’ acknowledgment of confounders and bias,
3. Instrument construction/validity,
4. Analysis appropriate to the aims, objectives, analysis and reporting.

This type of critical assessment in cross sectional studies that are using graded Likert scales have limitations but were nevertheless useful in exploring the rigour of studies included and evaluating their weight in the interpretation of findings (Norman, 2010).

Intervention methods assessment:

Using a modified Template for Intervention Description and Replication (TIDieR) the following questions guided the assessment of interventional studies (Hoffmann et al., 2014).

1. Has the intervention been described in sufficient detail to be replicated?
2. Was there a rationale, theory or goal?
3. Were the intervention controlled and the control intervention described?
4. Was there a plan for monitoring adherence?
5. Was the intervention delivered as planned?

Although this study aimed to be exploratory, the rationale of including interventions and the validity of their findings could provide themes that support further inquiry (Hoffmann et al., 2014).

2.1.4. Analysis with mixed methods integration

The analysis used a basic thematic frame to break up data, which included a predetermined thematic coding that lead to the generation of conceptual themes related to the research question. This is described in the following section about descriptive and conceptual framing. The selected qualitative studies were incorporated into an Excel database to facilitate enquiry and classification and to generate documents with coding and interpretation of text from different studies. Quantitative and intervention studies were examined using an Excel table to visualise and compare the studies descriptive characteristics and contents.

The review analysis commenced with qualitative data to provide the main conceptual themes. These were considered to provide in-depth insights, therefore providing data congruent with the methods of the planned study of practitioners. Contents were indexed, compared and synthetized to identify main themes. Quantitative and intervention studies were aligned to the themes arising from qualitative studies and contributed to the interpretation of evidence. When emerging themes were not already addressed by any of the qualitative themes, a new index theme was created and further analysis undertaken to identify linkage with main themes. When proceeding to evidence synthesis the main themes were examined for cross cutting concepts. In interpreting findings both content and conclusions of studies were critically examined, compared and contrasted within and between qualitative papers and the results of quantitative surveys and interventions;

then summarized, and interpreted in relation to themes associated to access to health care (Heyvaert et al., 2011).

Descriptive and conceptual framing

A descriptive indexing list incorporating basic categories was used to classify and break up the data from qualitative papers. The basic thematic frame was based on discussions with supervisors and based on the wider literature review. Modifications were needed to adapt it to the practitioners' studies where the indexing reflected areas of the process of interacting with patients and with the condition. The indexing intended to identify findings related to attitudes of practitioners toward chronic hepatitis B, toward the population and toward the health system policy and guidelines. The index matrix also contained constraints or facilitators at different levels, behaviour and practices and training issues that could emerge from the studies as shown in Table 2-1.

Table 2-1 - Basic matrix for indexing the content of studies

Main index	Sub-index	Meaning
Attitudes / insights	About population About HBV About policies/ guidelines	Findings indicating insights practitioners' have towards these particular areas
Role insights	Practice / behaviour Training issues	Description of current practice or training received
Constraints / facilitators	Institutional Service Time	Admission of possible barriers or facilitators originating on any of these themes
Wider issues	Socio-economic issues / interaction	Admission of possible barriers related to topic

2.2. Descriptive findings

This section describes a sequence of descriptive outputs. These include results of search, sifting and selection of studies; and quality assessment for the different methods used in publications.

2.2.1. Search results

The original search was carried out in 2014 and produced 347 papers after excluding duplicates. The two initial sifting stages aimed to select papers first that addressed hepatitis B, and second that focused on health care access for the populations intended. This resulted in 111 publications. Among these were 10 publications addressing practitioners. The assessment of richness and quality explained in the previous section excluded two studies not considered to provide sufficient data for analysis because they only assessed knowledge without assessing any other factor. A table showing the assessment of these two studies can be found in Appendix 2.4.

A limited updated search carried out in 2016 found two papers including practitioners and these were included for the publication of the wider systematic review. These were a qualitative study based in UK and a quantitative study based in USA, both published in 2015. A further quantitative study based in Europe published in 2016 was identified by limited search and included for the purpose of this thesis' discussion. Although these last three publications did not inform the design of the study, I incorporated these to make the search relevant to informing policy and practice and to inform the interpretation of this study.

In summary, the literature review incorporated 11 publications. The number of studies resulting from the search and selection of studies are described in the following flowchart (Figure 2.1). Table 2 describes the publications' authors, year and geographical location, general method and aim, health service setting, and type and number of participants.

Figure 2-1 - Search strategy flow chart

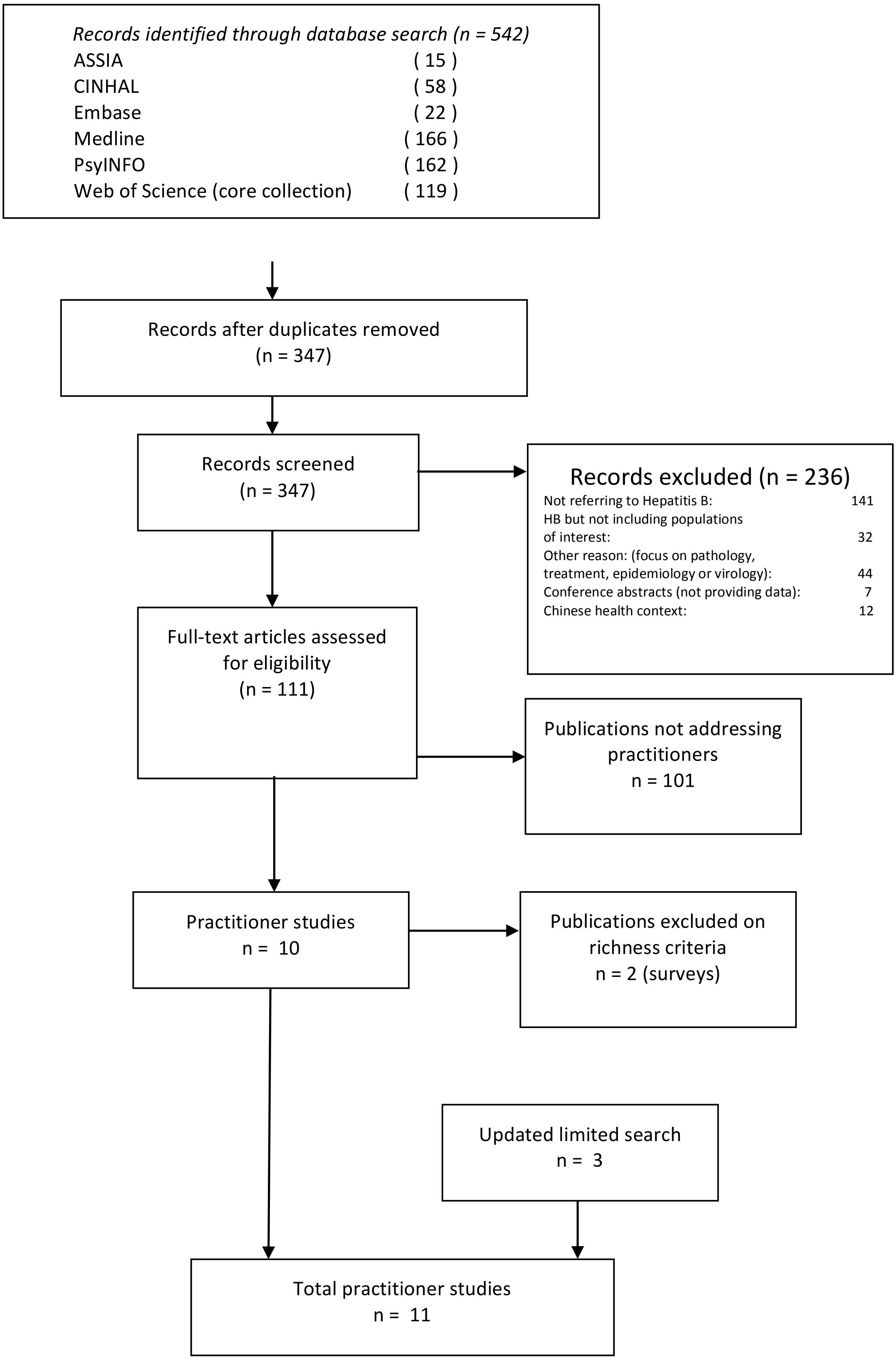

Table 2-2 - List of the 11 publications selected for review with study details

Author, year, location	Method	Aim	Participants (n)
Qualitative evidence			
Sweeney, 2015 London and Bradford (England)	Semi-structured interviews	To explore experience with HBV testing and treatment, and to assess acceptability of *HepFree* programme	General Practitioners in Primary Care (6), health practitioner key informants (17)
Yang, 2013 **Santa Clara county, California (US)**	Semi-structured interviews	To explore reasons for poor HBV knowledge and delivery of education to HBV positive pregnant women	Obstetricians (16), Perinatal Nurses (17)
Hwang, 2010 **Texas (US)**	Focus groups	Explore HBV beliefs, attitudes and practice patterns	Primary Care (6), liver specialists (9), other providers (8)
Quantitative evidence			
Bechini, 2016 England, Germany, Netherlands, Hungary, Italy and Spain	Cross sectional	Role of GPs in testing and managing patients at risk for HBV or diagnosed with chronic hepatitis B	Primary care physicians [GP] (40) and secondary-care specialists (64)
Chao, 2015 **Santa Clara county, California (US)**	Cross sectional	To examine incremental gains in knowledge after graduation	Total Physicians (219), interns (63), second year residents (60), chief residents (26), attending physicians (70)
Chu, 2013 **New York, Los Angeles, San Francisco (US)**	Cross sectional	HBV testing and vaccination practices of Asian American primary care providers	Primary Care Providers (217)
Chao, 2012 **Santa Clara county, California (US)**	Cross sectional	To assess level of knowledge and current prevention practice in perinatal nurses	Perinatal nurses (518)
Upadhyaya, 2010 **Multiple cities (US)**	Cross sectional	To explore attitudes towards HBV and current practice of testing, vaccination and management	Physicians with ≥200 patients a month and ≥5 HBV patients (total: 393), Internal Medicine (220), Primary Care/Family practitioners (173)
Lai, 2007 **San Francisco, California (US)**	Cross sectional	To explore providers' levels of HBV knowledge and testing practice	Total Clinicians (91), residents (55), faculty or fellows (33), nurses (3)
Weinberg, 2001 **San Diego county, California (US)**	Cross sectional	To explore preventive counselling of patients with HBV, and whether recommendations for vaccination were followed	Providers (65) including paired provider/patient (32)
Intervention			
Hsu, 2013 **San Francisco, California (US)**	Randomised controlled trial	Effectiveness of electronic prompt in ordering and completing testing for HBV	Primary care physicians (76: 38 each intervention and control arms)

Assessing the published literature

The following section, describes the assessment of quality and rigour by methodology.

2.2.2. Qualitative evidence

Qualitative health research in this area is scarce, only three papers were found that addressed practitioners, directly examined chronic hepatitis B, and discussed or considered populations of Chinese ethnicity.

Summary of quality assessment of qualitative evidence

The methods were examined using the questions described in the methods section (2.1.3) and the results are summarized in Table 2-3.

The quality indicators for the qualitative studies showed these were not entirely satisfactory. It was thought that the lack of reflexion on researcher influence and on limitations may have resulted from restrictive word count of publications. Nevertheless, the content of the studies was considered of sufficient richness and relevance to deserve exploration and none were assessed as having insuperable failings.

Table 2-3 - Methodology assessment for the three qualitative studies

Congruency/acknowledgment	Sweeney 2015	Yang 2013	Hwang 2010
Researcher influence/bias	One interviewer, influence and reflexivity not mentioned.	One interviewer to avoid variability, influence and reflexivity not mentioned.	Focus groups moderated by same researcher. Researcher influence and reflexivity not mentioned.
Methods/research aims	Congruent, informing knowledge, belief and attitudes towards Chronic hepatitis B to help with design of intervention. Assessed by qualitative methods in three participant groups and grounded theory analysis.	Congruent, aims to understand barriers to perinatal HBV education and counselling. Assessed by interviewing doctors and nurses and grounded theory analysis.	Congruent, aimed to "understand and elucidate the beliefs, attitudes and practice patterns of medical providers serving Asian American communities".
Recruitment method/bias	Recruitment is not clearly described; key informants recruited within health and lay organizations and only a small sample of GPs agreed due to time constraints. Diversity of key informants aimed to avoid biased data.	Letters, flyers, and in-person recruitment at four of the ten birthing hospitals in the county.	Purposive sampling, mail and follow-up sent to all eligible physicians in a large sample compiled by authors, groups conducted at restaurant with reimbursement of meal cost.
Limitations influence	Acknowledges limitations of small sampling and selection bias of small GP sample and of community participants.	Acknowledges limitations of small non-representative sampling.	Limitation acknowledged in non-representative sample of which half did not train in USA, and were mostly male.
Questions/findings/ interpretation	The questions were direct but aimed to be open, overall congruent with findings and interpretation of findings.	Findings mostly descriptive, some interpretive findings, questions appropriate to aims.	Questions congruent with aims and findings, interpretation of findings sometimes congruent, but some based on assumptions.

Methods, setting and participants

Of three qualitative method papers, two included collecting data through semi-structured interviews and one used focus group discussions, all described using grounded theory in the analysis. One study based in England interviewed practitioners (n=6) and key informants (n=17) that are involved in the pathway to diagnosis and/or counselling related to chronic hepatitis B (Sweeney et al., 2015). A second study interviewed obstetricians (n=16) and perinatal nurses (n=17) who provide counselling of pregnant women with chronic hepatitis B in California, USA (Yang et al., 2013). A third study carried out in Texas, USA, used focus group discussions with participants grouped in three categories to facilitate sharing of experiences. Two groups comprised practitioners involved in chronic hepatitis B diagnosis and management, one of primary care participants (n=6) and one of liver specialists (n=7). A third mixed group (n=8) included practitioners likely to come across patients with chronic hepatitis B in their professional work (Hwang et al., 2010).

The only UK based study in this review described a qualitative evaluation of existent barriers and of attitudes towards a proposed viral hepatitis (B and C) management programme based in primary care (Sweeney et al., 2015). The study reported the results of interviews with general practitioners in contact with the affected populations in addition to results of focus group discussions with a number of affected populations including Chinese. To inform the study, the researchers first interviewed key informants; these included community health workers, health service interpreters, hepatitis nurses and specialist doctors in viral hepatitis and sexual health. The interviews with key informants provided an insight into the needs of the groups affected and difficulties experienced in providing care for chronic hepatitis B. Although the aim of the study by Sweeney et al. (2015) was narrow, many factors emerged during the study of practitioners that can be identified as potentially affecting access. The authors explained that the inner city settings in London and Bradford were conducive to explore views of practitioners already involved in caring for affected groups including Chinese, in many cases in charge of diagnosing viral hepatitis B and C, and who would have an informed opinion about the upcoming pilot programme.

The two qualitative publications from USA were carried-out in areas of high density of Asian American residents. One study used semi-structured interviews to explore views of obstetricians and perinatal nurses on barriers to providing education and awareness of hepatitis B and prevention to their patients. This was set in Santa Clara county where resides one of the largest populations with the highest risk of vertical transmission of HBV. The study explored reasons underlying low knowledge and factors affecting delivery of preventive education (Yang et al., 2013). The study followed a previous survey done in the same area that found low knowledge and insufficient preventive counselling around chronic hepatitis B in perinatal nurses and that is also included in this review (Chao et al., 2012).

A second USA qualitative paper was based in Houston, Texas and evaluated barriers to chronic hepatitis B management among physicians using three focus group discussions. Using purposive recruitment three different focus groups discussions were set-up to explore views from practitioners serving Asian communities. Two of the groups involved practitioners who actively diagnosed or managed chronic hepatitis B. The primary care group was comprised of internal medicine, primary care and general practice physicians, noting that there was no explanation of the differences in clinical practice of these different clinician groups. The second group managing chronic hepatitis B included hepatology and gastroenterology physicians. A third group of mixed practitioners who may come across people with chronic hepatitis B in their work included paediatricians, obstetrician/gynaecologists, other surgeons and acupuncturists. All these practitioners served the Chinese, Korean and Vietnamese populations resident in Houston (Hwang et al., 2010). The study reported that the groups were small and congruent in composition to allow conversation that is more familiar. The focus groups were run in restaurant settings during evening meals and expenses were refunded to participants for the meal.

Emerging topics within studies

The paper by Sweeney et al. (2015) reported a concern emerging from general practitioners about increasing workload and sustainability of a primary case based programme that could prevent its development. The policy implications were described as the need to continue consultation with primary care regarding support needed for the development of such programme. In addition, perceived barriers from key informants included the need to address language barriers including providing support for attending appointments, understanding the function of services and the need for information about the condition and its management.

In the paper by Hwang et al. (2010) the main emerging themes included barriers perceived by practitioners and these were financial and linguistic, also considering cultural preferences for complementary medicine was considered an important issue. Suggestions were given by participants to improve access and these included community venues and collaboration in raising awareness.

Yang et al. (2013) provided insight into low confidence of practitioners in counselling mothers affected with chronic hepatitis B. This was attributed to low understanding of the condition conveying fear of providing wrong information.

2.2.3. Quantitative evidence

The review examined quantitative evidence to see if it supported or contradicted the findings from qualitative evidence. In general, these publications provided insight into hepatitis B knowledge and reported practice, using methods such as Likert graded scales and descriptive statistics.

Summary of quality assessment of quantitative evidence

Seven quantitative studies were included and the assessment of methodological quality was done examining design of the study, instrument construction and validity, appropriateness of statistics and analysis, and the acknowledgment of confounders, bias and limitations; the results are summarized in Table 2-4.

Table 2-4 – Quality assessment for the seven quantitative studies

Author, year	Participants source, eligibility, recruitment	Confounder/bias acknowledged	Instrument construction and validity	Stats, analysis, richness
Bechini, 2016	Aimed to have representative sample (5 - 10/ care area/ country) by contacting board members of clinical associations and professional networks throughout Europe.	Warning about interpreting results where minimum number per care area and country not reached, other limitations or bias not mentioned.	Two semi-quantitative online surveys (Likert scales), pilot tested, translated into the national languages.	Descriptive and analysed using SPSS; rich study with comparison between responses from different areas of care and countries.
Chao, 2015	Recruitment of physicians from 2 centres, 5 specialties and 4 different training levels: incoming interns, outgoing interns, outgoing residents, and attending physicians.	Acknowledged limitations of selection bias of restricted areas of recruitment and self-reporting limitations.	Twenty questions with Likert scales answers, no mention of piloting or validations.	Provides sufficient descriptive data, and analysis results in several statements of comparison between groups.
Chu, 2013	Massive mail out to primary care providers with Asian names (15,000) in 5 large cities to identify those with at least 25% Asian American patients, willing to complete online questionnaire.	Considered limitations of selection bias by using online methods and interest bias and whether it was representative for other contexts.	Designed by clinician experts and an organization with experience in epidemiological online research: demographics, knowledge and motivations for testing.	Initial descriptive and percentage data, logistic regression for associated factors. Richness of descriptive data, diversity, clinical questions and insights into knowledge and motivation for testing.
Chao, 2012	Recruited perinatal nurses (obstetric in inpatient and outpatient, labour and delivery, maternity, nursery, and neonatal intensive care unit) at each of the eight major birthing hospitals. Attempted to assess improvement in knowledge after seminar.	Acknowledged self-reporting answers and lack of time for completion. Lack of long-term knowledge or practice change. Also, lack of instrument validation and generalization of findings.	Survey questions developed based on more than a decade of experience using surveys in the subject, exploring prevention and management practice and knowledge.	Not a rich study but related to one qualitative study (Yang et al., 2013) and studied a key area for chronic hepatitis B prevention.
Upadhyaya, 2010	Random selection of individuals of Chinese ethnicity and initial testing invitations sent by email to physicians using market research lists	Limitations recognized in relation to population but not in relation to physician participants.	35-minute online structured questionnaire for clinicians asking about attitudes, practice, guidelines on chronic hepatitis B.	Mostly descriptive stats, assessed a number of factors influencing practice and awareness.
Lai, 2007	Providers were eligible if they were a physician (resident or faculty) or nurse practitioner with a continuity practice	Limitations of university based practice not generalizable to community based, selection of patients, and reasons for not testing.	Survey developed by authors used case scenarios to evaluate practice, pretested with practitioners at another site and revised.	Not rich study but paired records of patients, comparing practitioner ethnicity on rate of testing, descriptive and logistic regression used well.
Weinberg, 2001	HBsAg test results reported during a 2-month period recruiting people with chronic HBV infection and their providers, 46% were pairs of patient and provider	No limitations mentioned in discussion.	Phone interview of non-pregnant patients diagnosed with chronic hepatitis B, and with responsible provider. No description of validation or pretesting.	Obtaining paired experience revealed differences.

Methods, setting and participants

Seven studies are described here, of which six were based in different areas of USA (Weinberg et al., 2001; Lai et al., 2007; Upadhyaya et al., 2010; Chao et al., 2012, 2015; Chu et al., 2013); and one recent survey included primary and secondary care doctors in six European countries including UK (Bechini et al., 2016).

Including publications originating in USA versus those originating in Europe posed a question of relevance for the study. The main difference was contextual, while there is a fee for service in USA; UK and other countries in Europe have universal access at point of care. The studies originating in USA were examined and considered to provide useful information despite the context difference. Consideration to context was given while undertaking synthesis of evidence.

Reported aims and emerging topics

All quantitative papers used cross-sectional surveys methods, and aimed to explore different aspects that are considered to influence access to health care services including practitioners' knowledge. Three publications explored practitioners' knowledge and testing practice (Chu et al., 2013; Upadhyaya et al., 2010; Lai et al., 2007). Two papers assessed knowledge and vaccination or preventive counselling practice (Chao et al., 2012; Chu et al., 2013) and two, knowledge and awareness of chronic hepatitis B (Weinberg et al., 2001; Lai et al., 2007). One more recent publication explored knowledge of chronic hepatitis B and the effect of medical training (Chao et al., 2015). Another recent paper enquired about general practitioners' knowledge, testing practice and awareness of referral and management pathways for chronic hepatitis B and liver cancer in various countries in Europe (Bechini et al., 2016).

Most studies were aiming to obtain self-reported clinical practice in order to identify factors that could be affecting either testing or management of hepatitis B. Some studies were narrow in their aim and only assessed knowledge in relation to practice (Lai et al., 2007; Upadhyaya et al., 2010; Chao et al., 2012). Other papers extended their aim to assess effects of training (Chao et al., 2015), the effect of concordant ethnicity (Chu et al., 2013), and of organizational influence (Weinberg et al., 2001; Chao et al., 2015; Bechini et al., 2016). Bechini et al. (2016) study also aimed to document differences in health care and referral practice in several countries of the European region.

Highlighted findings were noted in the authors' discussions and conclusions. One of these was the inconsistency between recommendations and practice around HBV testing and immunization in populations at risk (Weinberg et al., 2001; Lai et al., 2007; Upadhyaya et al., 2010; Chao et al., 2012; Chu et al., 2013). Another highlighted finding was the importance of physician recommendation in the request for testing in fee for service systems (Weinberg et al., 2001; Lai et al., 2007; Chu et al., 2013).

2.2.4. Interventional evidence

One interventional publication was included in the review.

Summary of quality assessment of evidence for interventions

The interventional study was examined using method related questions described in section 2.1 that include whether the study was controlled and monitored for adherence, had clear rationale and whether described sufficiently for replication; and the results are summarized in Table 2.5.

Table 2-5 - Methodology assessment for intervention study

Question	Hsu, 2013
Described sufficiently for replication	Yes, well described and could be easily replicated
Theory/rationale	Lack of guideline adherence/ Trigger of self-regulatory mechanisms
Controlled	Yes, active and control of equal size and characteristics, intention to manage results reported
Adherence monitoring	Not applicable, single reminder whether triggered response or not, all steps planned completed
Delivered as planned	Reminder and following actions completed including results and actioning of tests – referral to services

Methods, setting and participants

The intervention study explored the effectiveness of a tailored electronic prompt to encourage testing using a randomised controlled design. Selecting Chinese or Vietnamese patient surnames where all details and appointment schedule were available and had not previously been tested, the study compared an intervention group of practitioners receiving and electronic reminder with a control group. A liver specialist sent the reminder 24 hours ahead of the appointment and this contained CDC recommendations, information about prevalence of HBV in Asia, and a list of appropriate laboratory tests. Practitioners were randomly allocated and results were compared in the number of patients for whom a test was ordered and that completed testing; in addition it examined tests results and whether the physicians acted on the results (Hsu et al., 2013).

Emerging topics

This intervention was well designed and was effective in the relatively small sample tested. The intervention sought to address the discordance between practice recommendations from American guidelines and actual practice. The discussion indicated that brief but effective measures could bypass some practice barriers and improve testing for chronic hepatitis B in populations that are known to have high prevalence of the disease.

2.3. Evidence synthesis

The following section describes main interpretive emerging themes from qualitative studies and the contribution of findings from cross sectional studies. In addition, indicative evidence of intervention effectiveness is described.

Themes emerging from qualitative studies

The themes identified from qualitative studies are discussed and compared to findings from studies using cross sectional sampling.

a. *Practitioners' report low confidence and knowledge of chronic hepatitis B resulting in inefficient practice. An intervention addressing this was effective in increasing testing of patients at risk of chronic hepatitis B.*

Several publications studied self-reported practice of testing and managing chronic hepatitis B. A qualitative study of practitioners involved in perinatal care highlighted practitioner difficulties in undertaking education of patients regarding chronic hepatitis B and preventing transmission, alluding to the lack of confidence in their knowledge of the condition. Antenatal practitioners reported that they were well positioned to provide preventive education but did not counsel pregnant patients routinely about chronic hepatitis B for fear of conveying the wrong message regarding the disease and transmission prevention (Yang et al., 2013). A previous survey of perinatal nurses by the same team had revealed that although the majority reported seeing patients with a diagnosis of chronic hepatitis B, only 51% routinely provided educational information. For example, while a majority of 75% informed the patients of the need for immunization of the new-born, only 62% made sure patients are aware that the full course is required and only 34% informed the patients about protecting household contacts. Knowledge level as assessed in this survey was low (Chao et al., 2012).

Similarly, a survey study, Chu et al. (2013), studied Asian American primary care practitioners with at least 25% of Asian American patients in their cohort. The study reported that of 217 practitioners, 41% confirmed that less than 25% of their Asian American patients had been tested and only 36% routinely tested these patients. Reasons included perception of lack of risk (47%) or lack of symptoms (36%); and a small proportion of practitioners (4%) reported that not testing patients was due to feeling uncomfortable treating chronic hepatitis B (Chu et al., 2013).

Several of the quantitative studies explored knowledge about chronic hepatitis B in practitioners but its correlation with practice was not consistently explored and improved knowledge did not always predict improved testing or vaccination practice (Lai et al., 2007; Upadhyaya et al., 2010; Chu et al., 2013).

In the study by Chu et al. (2013) reasons for testing Asian patients included abnormal liver tests, family history of HBV and symptoms of liver disease. However, only 62% of providers would test Asian patients with a close relative diagnosed with HBV or liver cancer. Asian primary care physicians were more likely to tests if they had a higher proportion of Asian patients, if the practitioner was born in Hong Kong or Taiwan, and if they had a patient diagnosed with liver cancer in the previous 12 months. Although better knowledge was identified in univariate analysis as correlated with testing (OR: 1.33 CI: 1.03-1.72), it was not an independent factor in multivariate analysis (Chu et al., 2013) indicating it may be a weak determinant. However, there are no studies large enough to demonstrate this.

In another study, most primary care physicians considered chronic hepatitis B a serious disease (83%), but universal testing of Asian patients regardless of symptoms was practiced only by a third of practitioners (33%); the remaining physicians (67%) would only test if other risk factors, symptoms or abnormal liver tests were present (Upadhyaya et al., 2010).

A survey study correlated rate of testing with knowledge score (10 questions), ethnicity and seniority, using self-reported practice. The study found that increased testing was reported by physicians that spoke an Asian language and those with a better score in the knowledge questionnaire in multivariate analysis; and there was no difference in knowledge between resident physicians and other physicians in bivariate analysis. Other physicians reported to test Chinese patients in 54% of cases vs. 27% reported by residents (Lai et al., 2007).

A more recent study identified that education in medical school and postgraduate training poorly prepared physicians in testing and managing chronic hepatitis B. The study explored correlation between professional experience and improved assessment of risk, and management of chronic hepatitis B. Knowledge of chronic hepatitis B was low and did not improve with increased experience and training. A majority of physicians (69%) had low confidence in their own chronic hepatitis B knowledge, and suggested that preparation was poor prior to graduation and during post-graduate training indicating this could act as a barrier to addressing the problem of undiagnosed disease (Chao et al., 2015).

In the British study by Sweeney et al. (2015), general practitioners thought that secondary care services could provide better services for patients with viral hepatitis. The reasons given included improved professional support and better familiarity with treatments; the study participants highlighted the lack of capacity in primary care to provide tailored services that require experience and knowledge (Sweeney et al., 2015).

The issue of practitioners' low confidence in their own knowledge and training is supported by the effect of one intervention (Hsu et al., 2013). In one randomised controlled trial of 175 patient visits to 76 primary care providers, a single electronic prompt was used with 88 patient visits seen by 38 providers in the intervention group. The remaining 87 patient visits to the other 38 providers were monitored without intervention. The intervention included a message sent by a specialist 24 hours before the appointment to the physician due to see the patient. The email identified the patient as a candidate for HBV testing, provided a brief summary of guidelines, panel of tests to be requested, and advice about how to evaluate results. The patients seen fulfilled a selection process to identify 18 – 64 year old non-pregnant patients with Chinese or Vietnamese surnames who had a scheduled appointment in a primary care clinic within the three-month study period. There were no differences in baseline characteristics between the intervention and control groups. Patients were randomized ahead of the appointment, testing rates before the study were determined for the medical centre, and these were around 18% for Chinese or Vietnamese patients. The results were analysed using an “intention to treat” analysis including patients that despite selection were not Chinese or Vietnamese (n: 8) and those that cancelled or missed their appointments (n: 21). The primary outcomes showed that 36 patients in the intervention arm (40.9%) and 1 in the usual care arm (1.1%) received an order for testing of HB surface antigen; follow-up indicated that 30 completed the test in the intervention arm (34.1%), but none in the usual care arm. Most patients receiving a test had been to see a physician for preventive reasons rather than with a specific present complaint. Secondary outcomes showed that four out of 30 patients tested (13.3%) were positive for HBV infection and 2 (50%) were referred to specialists (Hsu et al., 2013).

b. *Anticipation of cultural barriers, of fear of disclosure, and of population stigma about chronic hepatitis B, negatively influence practice*

In the study by Hwang et al. (2010) practitioners identified that cultural beliefs, language and low awareness of the seriousness of the disease among patients act as barriers to providing testing and treatment. Importantly, it also identified stigma and social issues such as fear of being targeted by governmental institutions. Although a majority (67%) of practitioners used interpreters in clinical practice and 51% spoke an Asian language when speaking with patients affected by chronic hepatitis B, there were concerns about how to provide information to patients. Participants suggested that failing to translate medical jargon even in the patient's own language threatens to widen barriers in education and treatment; and that engagement with community support may be useful to improve access to care (Hwang et al., 2010).

In the antenatal settings, practitioners focused on the patients' preferences arguing that if the patient did not provide "cues", practitioners may assume a lack of interest in the subject or even fear or stigma (Yang et al., 2013).

Key informants in Sweeney's study in England suggested that patients might not respond to an invitation to test, considering it low priority, as they may feel well. Other key informants suggested that fear of next steps such as invasive procedures, or suspicion that they may be targeted by immigration services may represent barriers too (Sweeney et al., 2015).

c. *The expectation of financial barriers for patients act as barrier for testing and treatment both in fee for health service context and in free at point of access services*

Many studies highlighted a concern among practitioners about financial barriers. These were mostly in the context of out of pocket expenses for testing and treatment in USA, but also in relation to poverty, and long hours of unregulated work in England. In USA practitioners felt deterred from testing if they were aware patients may not be able to afford health care and treatment, affecting also the decision to immunize (Hwang et al., 2010).

Although the cost of treatment for patients was not relevant in the English study, long working hours and limited employment rights were considered barriers to accessing care even if it was to be provided in local general practice sites (Sweeney et al., 2015). In other studies 37% of physicians did not test patients at risk of chronic hepatitis B due to predicting the cost of tests for the patient (Upadhyaya et al., 2010) and 33% due to patient's lack of insurance (Chu et al., 2013). The study by Chu et al. also reported that cost was a barrier for a small number of providers, 3% said that it was too expensive to test, and 4% found working with insurances cumbersome.

d. *Practitioners identify, and expressed frustration at support failures in the system*

In England, the qualitative study sought views regarding a pilot project to manage viral hepatitis in primary care; lack of time and resources were highlighted as potential barriers to move this practice to primary care. Some general practitioners expressed frustration at the lack of consideration for the resources required for continuing after the pilot phase, and highlighted that support from specialist services needs to be readily available for difficult decisions or complications of treatment (Sweeney et al., 2015). A recent cross-sectional European study of services indicated neither treatment nor monitoring is carried out in primary care in England.

Practitioners in US (perinatal nurses and obstetricians) reported frustration with lack of time in consultations, lack of accurate educational resources for patients, and poor dissemination of protocols or guidelines for HBV in contrast with those for HIV and influenza, and suggested that a national drive is needed to improve the current situation (Yang et al., 2013).

Other emerging themes

This section describes two additional themes emerging from cross sectional studies; it includes observation about the role of guidelines in one study and correlation between patient and practitioner reports in another study.

e. *Evidence that guidelines are rarely used by practitioner is scarce*

One study looked into practitioner awareness of national guidelines. A direct question in a survey showed that a majority (62%) of primary care physicians were not aware of main guidance such as the American Association for the Study of Liver Disease guideline, the 2008 USA treatment algorithm, or major studies addressing HBV treatment (Upadhyaya et al., 2010). This theme did not emerge as theme in any of the qualitative studies or other quantitative studies. Other authors mentioned guidelines either in the introduction or in the discussion and sometimes in both inferring that lack of awareness of guidelines could explain the results, but did not ask about this in their data collection (Weinberg et al., 2001; Lai et al., 2007; Hwang et al., 2010; Yang et al., 2013; Chao et al., 2015; Bechini et al., 2016).

f. *Practitioner and patient report of testing and counselling about chronic hepatitis B can be inconsistent*

One study attempted to gain information from patients and practitioners in San Diego, California in the USA (Weinberg et al., 2001). In this study, health care providers reported providing management for the majority of their chronic hepatitis B patients (86%). When patients were interviewed, 20% did not know they had been tested for HBV including 14% that were not aware they had tested positive. Although the management of chronic hepatitis B was undertaken by a majority of practitioners, not all recommended testing and immunization of sexual partners and household members (55%). Of patients with household or sexual contacts, 48% reported having been advised to have their contacts tested and vaccinated. Even a lower proportion of practitioners reported providing counselling about transmission (43%); when including all patients 16% reported receiving this type of counselling and this increased to 24% if only those aware of their infection were considered. Weinberg's study also explored the patient/practitioner pair responses available (n=32) and the comparison between reported practice were also lower for patients than for practitioners.

Other studies attempted to include parallel findings from either interviewing patients and practitioners (Upadhyaya et al., 2010), or correlating results with patients databases (Lai et al., 2007) but findings were not reported comparatively therefore contribution to this topic was not informative.

2.3.1. Key themes

The literature about the influence of practitioners on access to testing and health care for chronic hepatitis B in populations of Chinese ethnicity was not extensive but some relevant findings can be drawn.

- Anticipation of patients’ barriers such as stigma, fear of system involvement in official functions and lack of time or affordability could deter practitioners from testing and/or immunizing for hepatitis B.
- There was evidence that practitioners have low confidence in their knowledge of chronic hepatitis B and lack supporting systems of information. Electronic reminders were effective in one well-designed study.
- There was some evidence that self-reported testing and counselling can show dissonance when comparing practitioners’ and patients’ accounts.

These emerging themes contributed to understanding practitioner participation in access to health, and have implications for the research study of practitioners. I discuss the relevance of these findings in the next section.

2.4. Discussion

The findings of the literature review revealed that there is limited evidence. Although limited, the findings pointed to complex barriers acting within the different clinical contexts that could contribute to understanding factors related to practitioners.

The conceptual model of adjudication of candidacy and offer of services (Dixon-Woods et al., 2006) helped to identify key issues in relation to the research question. The clinical encounter was recognized as the best opportunity for a practitioner to inform and discuss key issues around chronic hepatitis B with individuals that may be at risk. Practitioner's lack of confidence in their knowledge and frustration with system support failures could predispose against discussing hepatitis B transmission with pregnant patients or offering test to patients (Yang et al., 2013). Among the reasons why Asian American physicians tested only some of their Asian American patients in the study by Chu et al. (2013), was lack of confidence in how to treat the condition or perception of lack of risk. The study by Yang et al. (2013) recommended effective education of providers and improved institutional awareness of the condition as tools to provide better care; but there is little evidence of the efficacy of this (Vedio et al., 2017). The scarcity of data on the effect of education measures in this area remains, but arguably awareness of the condition by practitioners, policy makers and the population has a role in the prevention of transmission (Hatzakis et al., 2011).

Yang's study highlighted barriers acting during pregnancy, a time that is key for the mother to be aware of transmission and to be engaged in preventing it in the perinatal period. In the UK, before August 2017, concordance with targeted immunization was necessary and these frequently failed (English, 2006; Beck et al., 2014). Although universal immunization addressed this lack in the UK, pregnancy and birth continued to be times where transmission to babies could occur from chronic hepatitis B affected mothers (Gentile et al., 2014). Many worldwide publications focused on how to medically manage to prevent vertical transmission including modifying vaccine doses (Lee et al., 2006), implementing services to actively follow-up mother and infant to complete targeted immunization (Larcher et al., 2001), adding antiviral treatments during the third trimester of pregnancy (Xu et al., 2009; Dusheiko, 2012). These solutions were focused on changing medical management in obstetrics or hepatitis services without addressing how to promote engagement of practitioners in general, or how to inform on prevention of transmission, and more importantly how to promote understanding and engagement by patients (Department of Health et al., 2011). Patient engagement could be a very complex issue for practitioners to address in isolation (Seedat et al., 2014); organizations have a responsibility to address the challenges individual engagement presents, especially with stigmatising conditions (Metzl et al., 2014).

Inconsistent service provision, lack of awareness of high prevalence of hepatitis B, and low confidence of practitioners in discussing chronic hepatitis

B were barriers detected and have the potential of acting synergistically to inhibit proactive practice. Sweeney et al. (2015) reported that time and lack of confidence in providing an effective primary care based service were highlighted by general practitioners in England when asked about the impact of such services. These practitioners also expressed frustration at a lack of foresight of the need for support from secondary services in complex situations making them reluctant to take such responsibility. The study by Bechini et al. (2016), undertaken in six European countries including England, highlighted that lack of clarity between the specific roles of primary and secondary care in the identification and care of patients with chronic viral hepatitis results in gaps in diagnosing and referring patients, and in turn accessing treatment. This uncertainty about responsibility for diagnosis and treatment also contributed to the uncertainty around management of chronic hepatitis B. Uncertainty was seen to contribute to failure of professionals to act flexibly and was disempowering, especially when dealing with culturally different populations (Kai et al., 2007).

Financial factors that were anticipated as patient's barriers were found both in USA and UK studies. Assumptions about financial and stigma based barriers stopped USA practitioners from testing if lack of affordability of tests or of treatment were predicted (Hwang et al., 2010; Upadhyaya et al., 2010; Chu et al., 2013) or if fear of diagnosis or stigma about the condition were thought to be prevalent (Upadhyaya et al., 2010). Although most financial themes emerged from a system where practitioners have independent fee based practices, financial factors were also applicable in England, such as poverty, cost of travelling, time taken from work, or other indirect costs (Sweeney et al., 2015). Practitioners' assumptions and barriers could potentially exacerbate lack of familiarity with the condition in individuals, and was associated with higher stigma score in patients (Cotler et al., 2012). Additionally, assumptions about patient's preferences without confirmatory discussion of preference, contradicted the idea of shared decision-making to reach a decision compatible with the individual's choice of health care action (Charles et al., 2006).

Equally, failure to communicate effectively even in the patient's own language were considered important barriers in engaging with prevention and treatment (Chu et al., 2013). Deficient communication is an extensively studied factor in health care services studies. The deficiency could be due to non-congruent-language or poor understanding of individuals by practitioners and could have serious consequences. These could include failure of understanding important information, failure to obtain consent and risk of clinical errors (Bowen et al., 2010). For non-urgent medical problems such as chronic hepatitis B, lack of communication may result in marginalization of underserved populations with the resulting increase in health inequity (Gerrish et al., 2004).

Many studies were based in areas with high proportion of uninsured residents, such as in California, providing evidence of barriers in a setting where demand for free services is higher (Weinberg et al., 2001; Lai et al., 2007; Chao et al., 2012, 2015; Hsu et al., 2013; Yang et al., 2013). The population with a high prevalence of chronic hepatitis B in many areas of USA was much larger than that seen in England and there are more health practitioners of Asian ethnicity. Practitioner's studies with concordant East Asian ethnicity reported some improved practice in relation to communication but findings were not conclusive (Hwang et al., 2010; Chu et al., 2013; Yang et al., 2013). Practitioners of Asian descent and that spoke the language, expressed doubts about individuals' understanding of the disease, mentioning difficulties in explaining medical terms in simple language. This may be related to difficulties in making clear how chronic hepatitis B may affect life expectancy and morbidity. A qualitative study have shown that Malay and Chinese patients attending secondary care in a large city hospital in Malaysia may experience distress and not comprehend the difficult concepts regarding chronic hepatitis B, but that the outcome is dependent on the way practitioners conveyed the concepts of risk and complications (Ng et al., 2013).

The study by Ng et al. (2013) also pointed out that most guidelines did not provide pointers about what would be appropriate to discuss pre-testing and after a diagnosis is established. This is true of the 2012 European guidelines (European Association for the Study of the Liver, 2012); and the newer European guidelines (Lampertico et al., 2017). However, a recent book produced by the World Health Organization in Geneva specifically addressing testing for viral hepatitis, included a chapter section about pre and post test counselling (WHO, 2017). The publication defined what advice to give those who test positive and included some structure for discussion. These points include: - explaining results and diagnosis, - providing clear information on further tests, - discussing and making an active referral to a viral hepatitis service, - providing advice on how to prevent transmission of infection, - other general points regarding life style, confidentiality, testing of family and offer of immunization to contacts. Although this may not be helpful to physicians that are not familiar with the condition, the document provides a clear structure for post-test counselling practice and the information needed to convey. The advice could help overcome the lack of knowledge and confidence in practitioners about chronic hepatitis B. However, it is important to highlight that despite the wide availability of guidelines, there was little awareness and use of these (Upadhyaya et al., 2010), indicating that the existence of guidelines is not sufficient to shift practice.

Despite the low amount of literature found this review has strengths and these are discussed here.

The focus on qualitative studies helped explore mechanisms acting as barriers and quantitative studies supported the findings from larger practitioner populations. In addition, the effect of one intervention supported the findings by demonstrating effectiveness in bypassing some of the barriers with one simple reminder.

The varied settings for the studies provided information about barriers that are likely to be relevant across diverse clinical contexts. For example, the review included a mix of practitioner roles both in primary and secondary care and practitioners working in complementary health care, addressing areas where individuals may present with different needs. This inclusiveness allowed comparison of the practitioners' report of barriers experienced in providing health care in different contexts.

Among limitations, the search excluded publications not in English that could have provided further data. The review included publications only referring to hepatitis B and Asian or Chinese populations, and this may have excluded publications that look at more general barriers of access to health care that affect Chinese populations, or of barriers to hepatitis B care in other populations that could be transferable.

The resulting literature obtained included only three qualitative studies and only one was based in England where the health system is free at the point of care. The majority of studies took place in the US. In addition, the low number of qualitative data studies is important due to the relevance of qualitative research in understanding mechanisms acting at a time practitioners negotiate the offer of care with individuals within the NHS context.

2.4.1. What has not been studied

This section identifies areas that are not addressed in both qualitative and quantitative studies.

There was a lack of use of theoretical models to support the studies. The exception was the study by Sweeney et al. that suitably quoted the candidacy model by Dixon-Woods el al. (2006).

In researching practice, there was no direct exploration of views and practice regarding shared decision-making and the perceived effect of power-over and the effect of structural stigma and racism in the interaction with individuals in the clinical encounter (Murray et al., 2006).

Additionally, what support is available to practitioners was scarcely explored in most studies. Only one single intervention showed that timely targeted support for clinicians resulted in significantly improved testing and diagnosing of chronic hepatitis B in patients at high risk of infection, especially those presenting for less urgent consultations (Hsu et al., 2013). This has not been reproduced in other contexts or in larger cohorts.

Identifying how adjudication and offer from the candidacy model (Dixon-Woods et al., 2005), and shared decision making in the clinical encounter (Charles et al., 2006) influence health practitioner's work in England, particularly when encountering populations of Chinese ethnicity and chronic hepatitis B, need exploring.

2.4.2. Summary of key points from the literature review

This review showed that there is a scarcity of well-designed studies involving practitioners as key actors in facilitating access to health care for populations of Chinese ethnicity.

The majority of studies were based in USA and were cross sectional, with only two in USA and one in UK that aimed to elicit in-depth knowledge related to practitioners using qualitative methods. The qualitative study based in UK was limited to an exploration of barriers to plans of service delivery based in primary care.

Conclusions derived from the literature review contributed and informed this study by providing a knowledge base and identifying areas that required further exploration. Areas of the clinical encounter that remained unexplored included factors influencing decision-making for this particular condition and availability of support for practitioners to focus in low priority conditions such as chronic hepatitis B that significantly affect groups of Chinese ethnicity.

2.5. Conclusion

This review provided a platform to understand what factors have been studied that respond to the research question. Multiple factors could affect practitioners’ roles in access to health care and treatment for chronic hepatitis B in individuals of Chinese ethnicity. Although there was an indication that multi-layered factors could synergize and increase barriers to the receipt of appropriate care, in-depth qualitative evidence is scarce and provides little insight of how these apply in the national context.

2.5.1. Implications for practice and further research

The implications for practice relate to low awareness about chronic hepatitis B and how can this translate into an effective practice to ensure people affected can access health care timely. Awareness that migrant populations of East Asia including those of Chinese ethnicity require health care for this condition was an important factor for effective service provision. Engagement of individuals, practitioners and services may be an important determinant in developing effective clinical practice and changing policy. For example, the lack of regionally or nationally co-ordinated practice as shown by Bechini et al. (2016) indicates the need for evidence about how entrenched is this gap in coordination, and what is the impact in service provision and clinical care, and ultimately in access to health care.

At a clinical encounter level, the lack of awareness affecting practitioners seemed to be effectively bypassed by quick and timely reminders that explained guidelines in one study (Hsu et al., 2013). Reproducibility and efficacy of this simple measure in different situations or contexts is not known. Other issues such as competencies in communication, transcultural care and shared decision-making could still be important issues in this case. There was a trend towards better practice and understanding in ethnically congruent physicians and this could be a relevant issue to explore in UK health care provision. The rest of this thesis presents the primary research undertaken to elucidate these issues in more depth.

3. Research methods and descriptive results

This chapter delineates the study design. The study methods entailed choosing a number of conditions that could ensure value and credibility of the research, including a reflective account of the methods and implementation of the study design. This research explores the experiences and perspectives of practitioners in their encounters with individuals as patients that can throw light into health care services' processes enhancing or hindering access to health care.

This chapter has five defined sections. The first section describes the study research perspective, including the rationale for the ontological and epistemological approaches and reflexivity on the purpose of the qualitative method used. Reflexivity also includes ethnicity, and patient and public involvement in research. The second section details the aims and objective of the study, the definition of the sample strategy, and the interview topics and themes. The third section describes the approach to contextual and descriptive analysis, and the process used in interpretive analysis and generation of conceptual outputs. The fourth section describes the ethical issues to consider for this study and the fifth section includes the descriptive findings of the participants' sample, interview data and initial data analysis.

3.1. Research perspective introduction

The research perspective includes the ontological position or philosophical approach that explains the nature of the reality to be studied, and the epistemological approach that determines what there is to know about the reality and how it can be known. I try to position the study by following definitions obtained by reading the literature in the subject. Understanding the major positions helps the researcher define the type of data that can be expected and the outputs that can be drawn from the research process. However, it is important to notice this is not a straightforward endeavour. In defining philosophical positions, different authors use different definitions to similar terms that can lead to confusion, as these can be overlapping and even at times contradictory. I do not intend to describe these differences here. It is important to note that an active process rather than a passive alignment with a position is favoured in qualitative research (Mason, 2002 p 54). I used two main texts to explore qualitative research; these are Mason's (2002) "Qualitative Researching", and Ritchie's (2014) "Qualitative research practice: a guide for social science students and researchers". These main authors are cited to indicate the author's position; for concepts derived from other authors, I include the original source of the theory.

I am a practitioner and as such have been involved in learning from research studies that are underpinned in biomedical frameworks. In biomedical studies, context and subjectivism are controlled as much as possible to eliminate their influence on the results and synthesis are aggregative aiming to find causal links; this is the positivist epistemological position. Learning from positivist studies has been central in my training and practice. The process is led by a diagnosis centred system of thought, with the overall aim of preventing and treating diseases to prevent premature death or disability. To carry out this research I needed to engage in a process of exploring and deconstructing the positivist basis of my experience in medical training in order to understand the other philosophical positions that can help in providing answers to different types of research questions. The next sections describe the philosophical positions that were adopted for the study.

3.1.1. Ontological position and epistemological approach

Ontology aims to explain the nature of the world to be studied. Two main schools of thought differ in their approach to whether there is a reality outside of our beliefs and understandings that can be known. This is the position of realism. Where reality is considered to be purely constructed and dependent on our beliefs and understandings, it is the position of idealism or relativism (Ritchie, 2014).

I chose to align the study with subtle realist ontology. Subtle realist ontology infers there is a reality that can only be known by our experience and interpretation of it, incorporating in this manner aspects of subjectivism and cultural assumptions (Blaikie, 2000). This is an exploratory study of practitioners' experiences, views and self-reported behaviour; subtle realism provides a coherent mid position between naïve realism (or positivism) and the idealist position of constructivism. This position helped me identify the study as situated within organizations. In organizations, there are multiple human interactions, social norms and values. Most norms and values develop in the context of a majority culture within which health services were created and continue to function and change. I aim to capture the current social reality by exploring the perspectives of different practitioners in various roles that can lead me to understand the facilitating factors and the barriers I seek to identify.

These processes can be studied by using interpretive epistemological approaches. Understanding interactions between individuals working within health organizations and with individuals requiring health care would be appropriately explored by an interpretive epistemology. This could allow building knowledge about factors through participants' observations of the world. With this in mind, the study aims to understand the reality of the practitioners' work context and the circumstances attached to making decisions with patients. The research aims to draw on the participants' own interpretation of the reality that exists. The interpretation is subjective and is influenced by context and personal experience. Multiple perspectives can help to build core concepts of interactions and to understand mechanisms that are involved.

3.1.2. Methodology

The methodology concordant with subtle realism and the interpretive epistemological position lies in the in-depth exploration of meanings and experiences and for this a qualitative approach is appropriate. By exploring practitioners' experiences and perspectives, I intended to recognize scenarios that can help identify the barriers acting in the process of access to care. Practitioners work in complex organizations and continuously seek to respond to needs of users of the service by applying knowledge, professional values, policies and available organizational processes to the problems that present before them. Their experiences, reported behaviours and attitudes could reflect the institutional and organizational norms and barriers that influence decisions before, during and after the clinical encounter, the central scenario of interaction between users and services.

There are also different types of intellectual puzzle that the research question represents. This study can be conceptualized as exploring the wider issues of influences pertinent to health services that can affect access. Exploring these influences through the views of practitioners is done using the example of a particular population in relation to one health condition. I aim to identify barriers to, and facilitators of, access to health care for a chronic asymptomatic condition that is chronic hepatitis B. Chronic hepatitis B is prevalent in a particular group of people whose ethnicity, for this study, is defined as Chinese. The research objectives are to produce practitioners' accounts as key participants in the interaction between individuals and services; and to identify emerging concepts and explanations for such findings. Models describing mechanisms such as adjudication of candidacy and offer of treatment (Dixon-Woods et al., 2006), and shared-decision making (Charles et al., 1999), guide the explanations.

Qualitative methods vary in their ability to produce data. In ethnographic studies, immersion and observation can be used and the data can be rich, in-depth and extensive, requiring researcher insight into this method (Spradley, 1979). This method was not considered viable or appropriate for this study of health practitioners. Ethnographic data was thought not be congruent with the research aim, and practicalities and ethical constrains were considered difficult to overcome. Practical issues included ethical issues of observing consultations, which are private, confidential and vulnerable situations.

Focus group discussions were employed for the arm that studied community factors. Focus groups stimulate discussion by means of guided questions or study vignettes and the interaction between participants can also provide clues about factors involved (Mason, 2002). For practitioners and other key informants this method was considered but discarded for reasons described below, these were discussed among the research team and in the advisory group forum. Key informants such as practitioners could have much to recall in their experience and may not need stimulation from peers, furthermore the influence of perceived hierarchy could prevent a truthful account, this is a known barrier for focus groups (Ritchie, 2014).

The safe and confidential environment that could be provided by individual interviews (Mason, 2002) was preferred to elicit data from key informants. The study was based on semi-structured interviews and this is described in this Chapter, section 3.2. Semi-structured interviews aimed to generate nuanced personal narrative and to explore meanings, values, motivation and decision-making experiences. Interviews represent confidential spaces for exploration, where a guided conversation unearths thoughts and experiences that are unique to the participant (Mason, 2002). The interviewer captures the interviewee accounts and how they are told within the interview context ideally in an environment that feels safe to promote disclosure. The purpose is to obtain an independent non-influenced account of their experience by using an unobtrusive interview guide (Ritchie, 2014). In practice, individual interviews were well received by potential participants and had the advantage of being more easily adaptable to a demanding work schedule and to the participant's preferred location for the interview.

3.1.3. Reflexivity

In subtle realism, there is an assumption that research cannot be value-free. For this reason the acknowledgement of values, biases and assumptions is essential, and researcher reflexivity and non-judgmental approach are important to in turn make the conclusions credible (Finlay et al., 2003). In addition, reflexivity about situation and context provides a framework for considering transferability to other contexts.

There are many ways to undertake reflexivity as described by Finlay et al. (2003), these modalities differ in what they can achieve and it is useful to acknowledge how reflexivity is used. In this study reflexivity was a process realized throughout the collection of data and analysis, and it aimed to have a critical stance of preconceptions and to acknowledge shortfalls of the research process. As a health care practitioner and the interviewer in the study, I was an 'insider researcher' and this position requires awareness of risks of bias, expected and unexpected blind spots and the striving for impartiality (Spradley, 1979). This was acknowledged especially during the interviews and carried-out into the analysis to ensure the conclusions were based in the data; the aim was to minimize the interference of tendencies arising from my work with chronic hepatitis B and the Chinese populations. The pathway of deconstructing the tendencies based on my own practice required a process of awareness and learning about the limitations of thinking from only a narrow point of view, be that of a professional and a specialist in the condition. In practice, I considered and incorporated diverse points of view expressed by members of the research team with different professional background, and from the advisory group for the wider study that also included members of the community who identified as Chinese, and were working to support people of Chinese ethnicity. I felt it was also important to reflect on how my characteristics, being a woman, being of white ethnicity and being a migrant could affect the process. I expand on my reflexivity findings in the Discussion Chapter.

3.1.4.Considerations about ethnicity

Research design and practice requires acknowledging principles that address ethical issues in regards to ethnicity. Reflecting on this, aimed to ensure that the approach did not contribute to increasing inequalities. Gunaratman (2003) in Chapter 1 of her book on “Researching ‘Race’ and Ethnicity” highlighted that researchers that wish to include the terms ethnicity and race, needed to address the problem these terms present if a reductionist, biological or close category approach is used. Instead, Gunaratman (2003) explained, research requires an understanding that these are historically and socially produced categories that have a political and oppressive meaning. This is relevant for the decisions that need to be made during the research process and to avoid perpetuating systemic inequalities (Gunaratnam, 2003).

Mir et al. (2012) elicited statements from worldwide experts and used a consensus approach to identify relevant principles that can guide research in ethnicity and health. The guidance was summarized as "The Leeds Consensus Principles for research on ethnicity and health" in the same article. The guidance established ethical responsibilities to incorporating appropriate evidence in relation to ethnicity and ensuring an overall aim of improving health. Some of these principles included the need for clarity about the theory that guides the research, including acknowledgement of within-groups diversity, using meaningful categories, recognising social factors, public participation in research and ensuring transparency and translation into practice. The authors warned about the potential harm that can be produced by lack of awareness of discriminatory language and research practices. Reflexivity about these issues are presented throughout this thesis, but can be summarized in the following points.

- The population that this study refers to is highly diverse, not only in socio-economic factors and education but in regards to country of origin, language, migration factors and ethnicity. The process of historical migrations from China to neighbouring countries and the self-selection of participants in the community arm of the study helped to define the concept of Chinese ethnicity.
- The study aimed to be inclusive and focus on Eastern Asian populations for whom the health need in regards to chronic hepatitis B is not being addressed effectively in the National Health Service in England.

- Awareness and challenging of the use of discriminatory language and practice was active during the research process and was guided by awareness of the principles listed in the “Leeds Consensus Statement”.

3.1.5. Patient and public involvement

The principles of research in ethnicity and health also required participation of the population affected in the design or undertaking of the research. In this study, invitation of practitioners and public representatives of Chinese ethnicity to the advisory group and to study consultation workshops addressed this particular principle. A public and patient group based at the local research office that involved patients of East Asian ethnicity affected directly or indirectly by the problem of chronic viral hepatitis participated in the design of the information sheets, consent forms, and provided feedback on the results of the studies. During the initial phase of the wider study, consultation workshops were held with members of a local Chinese community centre in Sheffield, the advisory group involved members of the Chinese organizations from different areas of England and Scotland. During the conclusion and dissemination phase of the study, feedback about findings was gathered in workshops in Liverpool, Manchester and Sheffield organized by Chinese community centres. In addition, consultation and dissemination workshops were carried-out with practitioners and key community informants in Sheffield and London.

3.2. Study design

This section describes in detail the steps of the study design. A study of factors embedded in the experience and views of health care practitioners could be best studied by using a qualitative approach. Qualitative methods are varied, but in this study, semi-structured interviews were considered appropriate for the collection of data followed by a thematic analysis guided by access to health care, cross-cultural care and decision-making models. In this section, I describe aims and objectives, method for data collection and strategies used in sampling and recruitment.

3.2.1. Aim and objectives

The research aimed to explore practitioners’ perspectives and experiences to help identify factors and aspects of their work that potentially facilitate or hinder access for diagnosis and treatment in patients at risk for chronic hepatitis B, in particular those of Chinese ethnicity.

The research question was expressed as follows:

- What are practitioners’ perspectives on, and experience of, factors that influence their work; and how do these factors contribute to hinder or facilitate access to health care services (including testing, treatment, immunization of contacts) for chronic hepatitis B affecting populations of Chinese ethnicity?

To achieve this aim, I set out to explore practitioners’ roles and responsibilities, and self-reported practice and experiences. The objectives included identifying the relevant sample and collecting data by qualitative interviewing. The aim of the interviews was to focus the questions to practitioners on the external and internal processes involved in assessing risk, in negotiating priorities, and in discussing decision-making with individuals. The interviewer enquired about the process of offering services such as testing and referral for treatment in primary care and offer of specialized tests and treatment in secondary care.

The specific objectives of the study could be defined as:

- To identify relevant areas of the NHS where testing of patients with hepatitis B is either universal (i.e. antenatal services, asylum and refugee services) or optional (i.e. main stream primary or secondary care) to help design a theoretical sample.
- To identify approximately 15 to 20 relevant practitioners that can provide meaningful data sources for the research question. These are practitioners that can provide first hand experience of the service provided and their interaction with patients with, or at risk of, hepatitis B, and/or of Chinese ethnicity.
- To ensure the interview includes exploration of practices involved in the clinical interactions and the identification of possible barriers to access to appropriate services until there is theoretical saturation of data.

- To ensure that the analysis is performed with the objective of identifying modifiable barriers and facilitators that can inform practice, commissioning, policy and future research.
- To ensure that the dissemination of findings informs translation into practice and research.

3.2.2. Sample strategy and recruitment

While planning recruitment, the research team and advisory group discussions concluded that certain health service locations and practitioners' roles were more relevant in evaluating risk and offering tests to people of Chinese ethnicity for chronic hepatitis B. It was thought necessary to explore the effect of exposure to a large number of patients with this condition and or of Chinese ethnicity. In addition, practices with lower exposure to this problem (practices in other inner city and rural areas) could offer data to compare and contrast experiences in different contexts. The different intensity of exposure to patients either of Chinese ethnicity or those affected with chronic hepatitis B was thought to influence clinical practice and attitudes towards patient's needs. In England, a patient's first port of call is primary care; therefore, practice nurses and primary care doctors were considered relevant subjects of study. Primary care practitioners who would have had higher exposure to people with such risk (i.e. Asylum and Refugee Health practices and practices with high number of Chinese patients) were considered relevant. These practitioners were considered more likely to provide narrative that is relevant to the research focus.

In addition, and to ensure different perspectives, secondary care practitioners were considered in areas where assessment of risk for hepatitis B was expected. Relevant areas included antenatal care where testing for HBV is mandatory in the UK since 2000 (Department of Health et al., 2011); dentistry practice, which is associated with risk of transmission (Mahboobi et al., 2013); sexual health where practitioners proactively offer tests for sexually transmitted infections and promote immunization of groups at risk (BASHH, 2015). Specialties such as nephrology, haematology or rheumatology consider the risk of transmission or reactivation of HBV during their procedures or treatments (Geddes et al., 2011; Shih et al., 2015). Finally, hepatitis specialists (infectious diseases or hepatology) could provide a point of view of the practitioner assessing and treating individuals with chronic hepatitis B.

In addition to professions and specialties, I sought to interview practitioners who self-identified as being of Chinese ethnicity to explore shared cultural experience and practice and to assess if there was a different perspective in understanding interactions with patients of Chinese ethnicity that could provide clarity and comparative data.

The sample design strategy aimed to be open to practitioners that could provide experience of working with populations that experience barriers accessing health care services in order to explore their perspective for significant information in regard to access to health care for underserved populations.

Table 3-1 – Strategy of planning for practitioners' sample

Front line practitioners	**Mother and child health**	**Sexual health**	**Specialties**	**Other**
Primary care*	Midwives*	Clinicians (doctors, nurses)*	Infectious Diseases or Hepatology*	Substance misuse services
Acute admissions (medical or surgical)	Obstetricians	Health advisors	Rheumatology or	Health promotion
Accidents and emergency	Health visitors	Health promotion	Nephrology or	Dentists
			Haematology	
			Dentistry	

* Four essential areas for recruiting participants plus at least one of other specialties mentioned (lists all areas thought to be able to provide data, but recruiting from all was not necessary)

3.2.3. Semi-structured interview preparation and guide

The rationale of using semi-structured interviews as the chosen qualitative method of data collection is discussed in section 3.1.2. The subjects of my enquiry were front-line health practitioners, including doctors, nurses, midwives or health promotion workers. Health care practitioners work for the National Health Service (NHS) in the UK, providing access to care for all eligible residents in the country. Qualitative interviewing aims to provide a platform for reflection by the interviewee based in the questions posed by the interviewer and questions should be open ended and impartial, avoiding suggestions or biases (Mason, 2002; Ritchie, 2014). The design of the interview included open-ended questions that could be adapted to different professions and contexts.

Interview guide:

Semi-structured interviews require certain conditions and a flexible structure to guide the process. For example, it is practical to start the interviews with an introduction and explanation of the study and consenting of the participant including consent for audio recording. In this study, after consent, a basic demographic questionnaire was completed at the start of the interview. General questions were then asked partly as “ice breakers” and the idea was to proceed from surface to depth of understanding. This was done by allowing topics to follow each other, allowing for flexibility and a heightened interviewer’s attention to identify and explore emerging themes. A number of topics were defined as essential points to consider with participants as follows.

(i) Exploring roles and responsibilities:

An initial aim of the interview was to understand the environment of work and roles of practitioners, and this was the first section of the interview guide. These were opening questions that helped to put the interviewee at ease, as the answers are related to areas well known by practitioners either established in their roles or starting a new job. These questions also could provide a step up to emerging themes or to expanding the answers if the roles seemed to be relevant to understanding barriers or facilitators of access to health care.

(ii) Exploring attitudes and interactions with patients of Chinese ethnicity:

Collecting experience of interactions with patients of Chinese ethnicity intended to provide a window into characteristics of the interaction, and to help interpreting previously expressed views from Chinese participants of the community arm of the wider study.

(iii) Exploring attitudes towards, and awareness of, chronic hepatitis B:

I called this part awareness rather than knowledge. It was suggested by team members of the wider study that gaps in knowledge was something we needed to know from both community and practitioners. However, the issue of the complexity and the protracted evolution of the knowledge required to understand chronic hepatitis B can present a difficult challenge when only positivist knowledge is evaluated rather than attitude, awareness and values (Wallace et al., 2017). For this reason, I did not ask knowledge-related questions except in certain circumstances when it was relevant to the conversation and could provide useful data. Instead I explored how practitioners think about infection risks to identify mechanisms involved in “adjudication of candidacy” and “offer of service”, the two main domains of the model guiding the study (Dixon-Woods et al., 2006). In addition, to explore further significant findings from the community participants when interacting with practitioners, I asked about attitudes towards requests from patients to be tested for hepatitis B. Also, I explored shared-decision making in offer of testing and referrals to specialist services. Insights into, and attitudes towards, patients and cultural differences were explored by asking practitioners to describe what they remembered about encounters with Chinese individuals when possible. These aspects were embedded also within the previously discussed exploration of roles.

(iv) Questions about views on barriers

When appropriate, at the end of interviews, participants were asked directly what barriers to access to health care in their view existed or they thought important to mention. This was also an opportunity to make any other contribution or comment they would want to add.

A summary guide for interviews and the framework for questioning can be found in Appendix 3.1 and 3.2.

The generic demographics and details of work roles were obtained from all participants by asking them to fill a form. The form included age group, gender, type of practitioner, years of experience in current role, previous relevant experience, institution and locations where they carried out their work, and self-identified ethnic group. The demographic details form is included in Appendix 3.3.

Interview recording and transcription

The interviews were audio-recorded using hand-held encrypted devices. The recorder was activated after obtaining consent from participants. A pool of university transcribers transcribed the full recordings verbatim. The interviewer corrected any errors of transcription by listening to the interview and using the transcript as a guide. Undertaking the correction helped becoming more familiar with the narrative and allowed the elimination of indirect identifiers to make the transcripts fully anonymous. Interview recording and transcripts were stored in a secure University of Sheffield server. Full anonymous transcripts were imported into NVivo® for breakdown and analysis.

Reflexivity about interviews

Reflexivity about interviews helped consolidate the need for ensuring neutrality and avoiding interpellations and interviewer's opinion. This is necessary to obtain non-forced responses that represent interviewees' views that are as honest as possible (Ritchie, 2014). Initially to practice this I studied sample interviews available from various online teaching resources, for example the online resource on Methods at University of Manchester by Professor Jennifer Mason. Initially, I proceeded to do a mock interview with a colleague that had previously undertaken a qualitative study to gather feedback on being neutral and asking open questions. In addition, the first interview was arranged as a pilot to see how well I was conducting this in the real world. The participant was fully aware of this and agreed for the data to be included in the study. I personally transcribed this first interview verbatim and obtained feedback from one of my supervisors who is a senior social scientist and who provided very useful comments especially in regards to probing questions and exploring contradictions further. For the following interviews, questions and prompts were adapted to enabling open and in-depth answers and allow exploration of the themes arising. Although an interviewer's position of neutrality and balance was intended, interactive exchange was not excluded, in this way the interview was a space for the interviewee to express their thoughts but allowing for questions to be asked back, taking care of not directing the answers but allowing the development of a relationship of trust (Ritchie, 2014). This approach facilitated flow, and helped develop conversations with purpose, a concept that contains within a two-way interaction, as a way to give back time for participants. In addition, participants with clinical responsibilities were given the option to ask questions about clinical doubts the practitioner may have after the interview was completed. In occasions, this exchange happened during the interview, when the participant wanted to clarify misunderstandings. After the interviews, I produced a summary of each interview experience and details that could have a bearing on the data. These brief summaries allowed identifying some areas to explore in future interviews.

Example of reflexivity to acknowledge preconceptions

This is a section of a reflective account done before embarking in interviews with practitioners that aim to understand my internal tendencies and biases.

> *"I am a Physician in infectious diseases; hepatitis B is one of my interests, this interest and the associated knowledge influence the way I would ask questions in that the questions will be more focused on the condition and less general about practice. This has advantages and disadvantages, the advantages are that I do know the complex pathway of the condition and what barriers in understanding to expect, how to change questions to learn about different attitudes or*

> *practices without confusing the important issues about the condition. On the contrary, having to ask questions from a general point of view or at a level where the pathway has not yet started is more of a challenge, for example: - How do people think about chronic hepatitis B? In which cases would it be considered a priority among all other priorities that a professional encounters and tries to address?"*

In addition, I wrote about how my role as interviewer could affect responses from participants.

> *"What are the ways in which my position as a physician may influence the responder? The responder may assume that I now a lot about their job and skip over areas that are well known to me especially if the interviewee is a colleague in the specialty or a doctor. Participants may have a defensive attitude if they think as a physician I am there to judge or find faults in their practice where there is a perception of hierarchy and I should try to bypass this preconception by being curious about the thinking process."*

These questions helped me to stay aware of possible power differentials and use prompts more readily to avoid assumptions. For example, assumptions about knowing the process or practice the participant may be describing could be avoided by ensuring that the answers are followed by clarification prompts.

3.3. Analysis approach

In this section, I describe the steps used in the analysis and how the theoretical models guided the analysis. It is important to clarify that analysis in a qualitative study is not a separate defined stage but a continuous process that overlaps with research design and the collection and indexing of data (Hinrichs et al., 2017 - Ch11, p217). Spencer et al. (in Ritchie, 2014 - Ch 11) present a detailed discussion of the processes of data management, and of abstraction and interpretation that helped develop the analysis for this study. A thematic approach was used by which certain themes considered important to the research question were identified and later grouped into categories that seemed natural to the themes (Braun et al., 2006; Ritchie, 2014).

To support the process of analysis and arrive at explanations a series of questions were put to the data in relation to practitioners' roles, based on the models used in the study. The questions aimed to provide insights into practitioners' experiences around the question of their role when interacting with individuals of Chinese ethnicity and thinking about CHB. The first question is related to the first part of the research question.

- What is the role of practitioners for this particular condition?

The aim of this question was to identify common emerging roles relevant to the research question that incorporate the domains of adjudication of candidacy and offer of services and point to elements of shared decision-making and cultural sensitivity.

- What factors influence the role of practitioners?

This question was broad but it could be divided in two main areas based on the behaviour wheel domains of personal or professional motivation and capabilities. The third domain, which is opportunities, addresses organizational factors and could be lifted or interpreted from the narratives.

Finally, a question was asked about particular experiences of practitioners.

- How do practitioners experience that role? What is their experience in relation to the population?

This question searched for individual or professional responses to population' needs or to challenges in organizations. By examining the data in this way, arguments were defined using practitioners' narratives.

The method used in the analysis was a self-developed method based on discussions with the research team, with supervisors and that resulted in the combination of steps from existent qualitative methodology. Steps of thematic analysis (Braun et al., 2006), Framework analysis (Ritchie, 2014 - Ch10, p283) and overall guidance by Ritchie (2014) Chapter 11, "Analysis in practice" guided the analysis described in the following sections.

There were three hepatitis specialists in the broad research team, including myself, who provided answers about ideal pathways of access for chronic hepatitis B. A senior social scientist from the wider team led the discussions and initial indexing codes were developed based on these discussions.

The initial stage involved indexing of data using these predetermined index labels. I call this descriptive stage of analysis and this is described next.

3.3.1. Descriptive stage

In the descriptive analysis demographic findings such as gender, age group and ethnic category helped exploring possible sample bias towards a particular group. Descriptions of roles, areas of work and type of practice, were used to understand content in relation to context within the study. Initial descriptive containers of data or indexes were tried iteratively with the data to find best match using the interview guide questions, relevant evidence and models and other basic themes that had emerged during the interview process that were considered relevant to the study. The process of breaking the data into containers or indexes also helped to identify common themes emerging from the data by comparing and contrasting narratives. It was essential to be aware of assumptions by the researcher while exploring transcripts (Ritchie, 2014). Therefore, indexing was a time consuming process that required attention to meaning and words, to ensure that selected text maintained veracity and relevance within the theme indexed (Mason, 2002).

Descriptive indexing of data

The main descriptive labels for indexing used were based on major pre-designed topics arising from the literature review, the community arm of the study and the interview guide, and were initially discussed with members of the team for the wider study and later with supervisors. In addition, as discussed above, expected health care pathways for chronic hepatitis B helped identify indexing codes that were important to explore. These labels helped structure the data and helped me to become familiar with each narrative. The aim was to compare and contrast data in order to identify common themes with a view to organize results into conceptual themes. To facilitate the indexing I incorporated the corrected anonymous interview text into the NVivo® software, this is a version of computer-assisted qualitative data analysis software or CAQDAS. The software facilitates the work of the researcher, providing electronic means of chopping and grouping data with the addition of category labels that can be applied to participants data and support cross cutting themes. The containers indexing the data in NVivo® are called nodes. NVivo® nodes were created to reflect perceptions and attitudes of practitioners towards individuals of Chinese ethnicity, towards chronic hepatitis B and towards the service context. Other nodes included practitioners' support systems, communication and language barriers, and practitioner insights about other relevant areas, and are listed in Table 3-2. Each node contained text selected that related to such topic, and if a fraction of text was indicative of unaccounted topics of interest, a new ad-hoc or *in-vivo* node was created.

These containers of data were the bases for the identification of emerging themes, which in turn informed the organizing or conceptual themes. The data generated cross cutting common themes, although some insights in primary and secondary care experiences were distinctive. This is a useful distinction to take in account for the contextual analysis as provides insights from different ways of working.

Table 3-2 - Basic descriptive labels used to structure data

Main node	Child-nodes	Explanation
Practitioner perceptions/attitudes	Towards chronic Hepatitis B	Any text indicating practitioners thoughts, experience or views on the themes described
	Towards patients	
	Towards service	
Support systems	Language	Descriptive or rationalized mention of any support systems in the categories described
	Information (printed/online)	
	Professional support/training	
Roles		Any professional role described
Other	Equity – underserved groups	Practitioners describing awareness of these and innovative services in response to need
	Culturally shared view	Practitioners explaining cultural behaviours
	Policy and guidelines	Reference or (lack of) awareness of such

Using access and behavioural models

The Dixon-Woods model of candidacy described in Chapter 1 (section 1.3.2), helped to explore mechanisms that affected or influenced the domains of practitioner adjudication of candidacy (the process of recognising the health need) and consequent offer of service; and how these in turn could affect access to care (Dixon-Woods et al., 2006). These mechanisms were qualified by the institutional context (the NHS), because of the difficulty in accessing low permeability services, and in the resulting attitudes and expectations of practitioners towards a condition considered of low priority nationally. In exploring behavioural and transcultural care concepts, my intention was to expand on the individual and organizational factors affecting the candidacy domains I was examining. It could be possible to explore further how to apply and integrate these concepts when discussing access to health care for vulnerable populations. For this step, it was useful understanding concepts of structural racism as discussed in Chapter 1, section 1.3.3.

To become familiar with the data, in addition to basic descriptive codes, the text was broken down also using the Candidacy model domains of ‘adjudication’ and ‘offer’, and insights into navigation and permeability of services, which are considered important factors of barriers in access to healthcare (Dixon-Woods et al., 2006). The components that affect behaviour and include capability, opportunity and motivation as described in the Behaviour Change Wheel, were also incorporated as nodes to break data and are described briefly in Table 3-3. (Michie et al., 2011). These were still considered descriptive codes with added conceptual layer that helped re-organise the data with a view to progression to identifying factors and developing explanations (Ritchie, 2014). These indexing codes overlapped with the previous descriptive indexing but helped with familiarization and identification of areas of relevance. In addition, some indexing was generated from the data and I have described it as ad-hoc indexing.

Table 3-3 – Descriptive labels that incorporate model domains

Main node	Child-nodes	Explanation
Candidacy	Navigation/ understanding	During the interview, participants identified or described processes intrinsic to patient encounter or journey through health services.
	Adjudication/understanding	
	Offer/ understanding	
Capabilities (practitioner)	Knowledge	Can include HBV, cultural competence, other
	Skills	Languages, communication, educational, other
Opportunities (system)	Service	Processes of the organization or service
	Training	Practitioner academic or practice education
Motivation (personal and professional)	Incentives	Refers to funding of activities
	Values	Personal and professional values/principles

Ad-hoc indexing

During the indexing process, some NVivo® nodes were created that highlighted some important messages so that these could be compared and contrasted between participants. These were called ad-hoc or in-vivo nodes as they emerged from the interviews' text. Four ad-hoc nodes were created called 'community engagement', 'entitlement', 'paternalism' and 'too much medicine' and are discussed in the descriptive findings in Section 3.5.

3.3.2. Interpretive stage

This stage required in-depth knowledge of the data, and the multiple indexing of data described before helped to become familiar with it. Conceptual themes emerged from the process that guided the categorization of the data (Ritchie, 2014).

In the process of comparing and contrasting narratives, the characteristics of practitioners in relation with the data were examined. It was noted that different specialties or roles provided different narratives. This was interpreted as the need to respond to a specific type of demand, and this helped focus the conversation around working patterns.

Generating themes and categories

Generating themes from the data required a process of familiarization. Comparing and contrasting experiences of practitioners working in different services helped identifying common themes and in formulating categories and interpretive ideas. Ritchie (2014, p 281) represents this graphically to show how data management helps abstraction and interpretation through an iterative process of identifying linkage between patterns and constructing categories. The process described by Ritchie (2014) evolves from organizing data to describing it and developing explanations. This involves an iterative process of indexing and reviewing data, constructing categories, identifying linkage and accounting for patterns. In this study the main themes emerged from this process. The categorization of themes resulted from the connections found between participants' experiences and perspectives as shown in Figure 3-1.

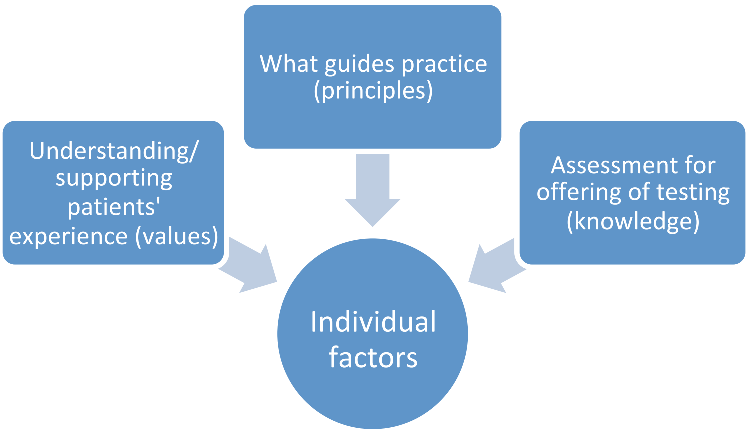

Figure 3.1 Example of drawing category individual factors from themes

As described in the previous section, I generated descriptive coding frameworks based on essential elements to explore, such as attitudes of practitioners towards different aspects of practice and also based on models that supported this study. For each interview I extracted data generated by this indexing codes, produced a summary of key themes and a memo of what appeared relevant. For all data, documents were generated from NVivo® that could be analyzed to find common themes. A brief example of this process is shown in Appendix 4.1.

Themes and categories constitute a bridge to identifying factors that can represent barriers. The processes of organizing, describing and explaining were the product of documenting commonalities and differences and these were used to identify and account for patterns and mechanisms.

The next section considers ethical issues in research.

3.4. Research ethics

Ethical issues in research include the core principles of integrity, quality and transparency. The study aimed to recruit practitioners via informed consent which was voluntary, and to maintain confidentiality and store data safely. The information and consent forms were submitted with the research ethics application and approved simultaneously. The wider study required a full ethics committee application as the population arm included a number of patients and larger numbers of community participants, a Research and Development element was incorporated in the full ethical approval and it was related to interviewing practitioners. The National Institute of Health Research (NIHR) later incorporated the study. Letters of approval are included in Appendix 5.1.

Information and consent

An information sheet was designed specifically for practitioners explaining the relevance of the practitioner study and the aims of the research question. The form included statements of confidentiality and freedom to withdraw without providing a reason. Input was sought from members of the research team and feedback from colleague practitioners helped with designing it. The information sheet was provided electronically a few days before the interview to give the interviewee the opportunity to reflect in their willingness to participate.

Voluntary consent was sought from all practitioners. For all face-to-face participants written consent was obtained. When direct interview was not possible both information sheet and consent questions were read again during the first part of the interview and I recorded consent after requesting verbal agreement. These alternative consenting procedures were included in the ethics application. The consent form and information sheet are included in Appendix 5.2 and 5.3.

Privacy, confidentiality and secure storage

When conducing the interviews it is important to ensure confidentiality. This is not only a requirement of well-designed research studies but also represents a reassurance that personal data will not be accessed by unauthorized individuals and the identity of participants will only be known by the research team. This in turn promotes confidentiality and encourages participants to be open in their responses. Since all practitioners employ confidentiality in their work and many had previously participated in, or carried out research this was promptly understood by all participants.

A safe physical storage place was designated for completed consent forms and physical agreements and contracts at the NHS site. A University server acted as storage for electronic data. The interview recordings were stored in this secure server. The interview transcripts and demographic details were stripped of any details that could identify the participant, incorporated to N-Vivo® and linked to each interview script and were stored at the same secure server. This was described in the Ethics application and research protocol of the wider study. Access to these files was only granted to members of the study group and these were kept in storage for the maximum limit allowed.

3.5. Descriptive findings: demographic details and professional roles

This section describes the contextual and demographic results, characteristics of the interview process and a summary of the descriptive data.

To acknowledge the clinical and organizational context of the data collected, participants' general demographics, type and general placement of work and their roles and responsibilities were included in the analysis. The study participants worked in wide-ranging health service environments and the demographics of participants were diverse. These findings set the context used to understand the narratives offered by practitioners who are working in the National Health Service. This contributed to finding explanations and factors involved in facilitating or hindering access to health care for chronic hepatitis B, particularly for individuals of Chinese cultural background.

The descriptive findings are presented here in stepwise sections. Demographics and roles of participants are followed by interviews' description, interview reflexivity and data description.

3.5.1. Participants' recruitment and sample description

The proposed sampling frame described in the methods section established the aim to recruit front-line practitioners whose roles were considered relevant to patients with chronic hepatitis B and of Chinese origin. The sampling frame purpose was identifying clinicians that could provide narratives of their experience in carrying out their roles. As discussed in sampling strategy, the research group and the advisory group were active in suggesting the type of practitioner that could be relevant to the study. Once the sample strategy was agreed, a number of ways were employed for the recruitment of participants.

- Convenience sampling: The research group provided a list of possible participants that were known to members of the research group and fitted the criteria of the sampling strategy (P1, P2, P7, P9, P10, P12, P13, P15). Of the original names in the provided list, many were not available to participate and other were superfluous to the requirements, for example participants belonging to that specialty had been already interviewed and data saturated.

- Purposive sampling: practitioners and key informants that were of culturally similar background or that participated in linking underserved populations to health care services were sought. Some were known to research group participants, two were recruited during casual professional events, such a research mandatory training and local research presentations (P14, P18, P19, P20, P21, P23).

- Snowballing: Participants from the convenience sampling provided suggestions of other participants that could be recruited and fitted the criteria for the sampling (P4, P5, P8, P16, P22).

- Research office recruitment: the wider study was adopted by NIHR and opened to other centres that chose to participate. Research offices that wished to participate were contacted to discuss recruitment and the Principal Investigator of the region provided names of participants. There were 3 participants in the group recruited in this way (P3, P6, P11).

The practitioners proposed for recruitment were contacted via email twice if no response received to a first email, and in occasion by phone if this was available. If no answer was received to a second email and no other mode of contact was available these potential participants were dropped.

During the process of interviewing, the original sampling frame was modified as participant data revealed either higher or lower relevance for service areas or due to saturation of data. For example, data emerging from interviewing sexual health doctors reached saturation. However, sexual health promotion workers that discussed barriers pertinent to underserved communities by describing outreach and specifically targeted work offered other insights relevant to some of the data obtained from previous participants. Another example of the modification of sampling frame was the need to recruit some key informants from the community to explore and clarify emerging data from clinicians in relation to working with community workers. These were proficient community workers supporting access to services that could provide an alternative view about factors acting in the interaction between patients and practitioners.

In total 23 participants were interviewed, including 19 health care practitioners, two health promotion officers working in sexual health services in community outreach and two community liaison workers with experience in the process of accessing health care by different ethnic groups. The sample was varied in age groups and was balanced in gender as described next. The health care professional roles included a number of occupations based in either in the community, or in primary and secondary care. The length of experience varied, this allowed having insight from practitioners at different stages of their career; for physicians, post-graduate training period was excluded due to the change in responsibilities associated with the full professional role. Table 4.1 describes the demographic details and professional roles of participants.

Participant demographics

The sample of participants was evenly distributed in terms of gender (F:12, M:11), age (<35:1, 35-49:10, 50-64:12), and professional working location (Primary care: 8, Secondary care: 10, Community based: 3 practitioners, 2 community workers). There was a predominance of experienced practitioners in their current profession (<1 year: 1, 1-5 years: 5, 6-10 years: 2, >10 years: 15). Participants' ethnicity groups included seven Asian participants, of whom three self identified as Asian Chinese, two as Asian other, and two as Asian British other than Chinese ancestry. There were two Black African participants, and fourteen White British participants. These ethnicities in part reflected the diversity of health services in the area, but also indicated purposive recruitment of Asian Chinese participants to explore shared cultural views. One participant from each location of work was recruited that responded as having Asian Chinese ethnicity. These included a primary care doctor, a secondary care doctor and one key informant representing a community setting. Table 3-4 provides a full list of participants by order of recruitment, indicating area of work, specialty and ethnicity. Discussion of main and other roles follows later in this section; participant numbers are grouped by setting and profession in Table 3-5.

Table 3-4 - Participants' demographics, roles and experience in order of participation

Order	Gender	Age group	Ethnicity	Profession	Main place of work	Experience (years)
1	F	50 to 64	White	Nurse	Primary Care	6 to 10
2	F	Up to 34	Asian	Doctor	Sexual health	1 to 5
3	F	35 to 49	White	Midwife	Community**	1 to 5
4	M	35 to 49	Asian	Doctor	Primary Care	1 to 5
5	F	35 to 49	Asian	Doctor	Primary Care	6 to 10
*6	F	50 to 64	White	Midwife	Secondary Care	1 to 5
7	M	50 to 64	White	Nurse	Secondary Care**	>10
9	F	35 to 49	White	Doctor	Primary Care	>10
8	F	35 to 49	White	Doctor	Secondary Care	<1
10	M	35 to 49	White	Doctor	Secondary Care	1 to 5
*11	F	50 to 64	White	Doctor	Primary Care	>10
12	M	50 to 64	White	Doctor	Primary Care	>10
13	F	50 to 64	White	Doctor	Secondary Care	>10
14	M	50 to 64	Asian	Doctor	Secondary Care	>10
15	F	35 to 49	White	Doctor	Primary Care	>10
16	M	50 to 64	Asian	Doctor	Sexual health	>10
17	M	50 to 64	Black	Doctor	Secondary Care	>10
18	M	50 to 64	White	Health promotion	Sexual Health**	>10
19	M	35 to 49	Black	Key informant	Community**	>10
20	M	50 to 64	Asian	Key informant	Community**	>10
21	F	50 to 64	White	Health promotion	Sexual Health**	>10
22	F	35 to 49	White	Midwife	Secondary Care	>10
*23	M	35 to 49	Asian	Doctor	Primary Care	>10

*Phone interviews (participants 6, 11 and 23)
** Main role is carried out in community settings
F: female, M: male
Experience = years working in current role
Full ethnicity not shown to prevent inadvertent disclosure (see text: participant demographics)

Table 3-5 - Practitioners recruited by main setting of service delivery

Community (n: 6)	**General practice (n: 8)**	**Hospital (n: 9)**
Midwife*	Asylum health nurse	Acute medicine Dr
Specialist nurse*	Asylum health Dr	Dentistry Dr
SH Health promotion officer*	Asylum health and MSP inner city Dr x 2	Infectious Diseases Dr
SH Health promotion manager*	MSP inner city Dr x 3 (includes 1 with large Chinese population)	Midwife x 2
Key informant x 2	MSP rural Dr	Nephrology Dr
		Rheumatology Dr
		Sexual Health Dr x 2

* Secondary care employed but working in the community; MSP: Main Stream Practice; Dr: doctor

Professional roles

The clinician participants that were interviewed had first hand experience of assessing, testing or managing patients at risk for chronic hepatitis B, or caring for patients of Chinese ethnicity in different service contexts. Primary care participants (n=8) included seven doctors and a practice nurse. Five of the primary care participants worked in mainstream practice with one occasionally working in an asylum-seeker-health practice. Three participants worked in asylum seeker health specialist practices, with one of them also working in a mainstream practice. Secondary care participants (n=10) included a specialist nurse, two sexual health promotion nurses, and doctors in acute medicine, infectious diseases, sexual health (n=2), rheumatology, nephrology and dentistry. In addition, three midwives were recruited from different geographical and service areas. Two community liaison key informants were recruited that had actively participated, researched or implemented practical help, to help access to NHS services by particular disadvantaged ethnic groups including Chinese.

The initial part of the interview asked participants to describe their roles and responsibilities and this produced a number of findings that highlighted the diversity of their roles and responsibilities, and of locations where services were delivered. Most practitioners had clinical roles that are complex, with many responsibilities and diverse geographical sites; for example, nursing homes for primary care participants; home visits in the case of specialist nurses or community midwives; and different hospitals or peripheral health units in the case of secondary care doctors. Non-clinical roles included medical or nursing education, health commissioning, public health roles, regional specialty leading roles, and research. For example, in educational roles, some participants were educational programme leads or academic postgraduate trainers, but undertaking general clinical teaching for doctors or students and undertaking appraisals for colleagues were not included within this role. Commissioning roles included involvement in the local Clinical Commissioning Group (CCG) or in regional specialized networks; public health roles included working in informing policy, participating in local or regional networks, working in public health sector and working as policy leads in NHS or other institutions. Finally, research roles included academic research and leaders in public participation in research.

A sample matrix helped to map the frequency of different roles reported across participants in the interviews, noting that it is possible that participants did not report all their roles. The roles' matrix is shown below with definitions for the roles as follows. Clinical roles are having responsibility for direct patient care, regardless of setting; the four non-clinician participants were involved in promoting access to health services for underserved populations. Formal educational roles include being named as professional educator or trainer or being involved in academic education. Finally, a research role is a formal academic role or public involvement in research rather than undertaking research as part of their clinical or other roles.

Table 3-6 - Matrix of practitioners' roles and area of work

Roles	**Primary Care**								**Secondary Care**								**Midwifery**			**HP**		**CKI**	
[Order number]	1	11	15	23	4	5	9	12	3	7	8	10	13	14	16	17	2	6	22	18	21	19	20
Clinical	A	A	A/M	M/A	MR	M	M	M	SH	C	IM	ID	D	N	SH	R	C	H	H	-	-	-	-
Link/ HP																				x	x	x	x
Education					x			x					x	x		x							
Commissioning							x	x				x			x								
Public health							x											x	x				
Research														x		x						x	

Headings: HP: health promotion, CKI: community key informant

Clinical roles: A: asylum health practice, M: main stream practice, (where combined, first letter indicates main workplace) R: rural setting, SH: sexual health, IM: internal medicine, ID: infectious disease, D: dentistry, N: nephrology, R: rheumatology, C: community (nurse/midwife), H: hospital

Link/ HP: facilitating access to services and/or health promotion as main role

Educator: practitioner has a formal role as clinician trainer or works in academic education separately from clinical role.

Commissioning: practitioner that forms part of clinical commissioning group or regional specialised funding.

Public health: role includes participating in public health body as clinician or public health officer separately from clinical role.

Research: Academic researcher or participates in national public involvement research bodies.

Non-clinical roles of practitioners provided further understanding how their experience could influence the responses given to questions in the interview. In the interviews, participants were asked to describe these other roles and the responsibilities associated with them. Involvement in education for example prompted discussion about training of practitioners in areas pertinent to the research, such as chronic hepatitis B with one participant and training in using interpreters with another. A participant involved in medical school curriculum described changes in medical education that aimed to improving communication skills in new student firms. A practitioner with a commissioning role was able to describe the difficulties in obtaining funding for a local enhanced service addressing the need of testing for HBV in a defined population. Public health involvement included assessment of the need for elderly people from minority ethnic groups and described how this need will increase locally in the next few decades. The research roles relevant to this study involved research in access to health care services for other underserved populations in one participant, and patient involvement in research, especially of minority ethnic groups in another. Both of these participants involved in research provided insight into barriers that are applicable to different minority ethnic groups and how it could compare with those of Chinese ethnicity.

Geographical location and differences in work patterns

The interviews provided data from a range of participating centres, mainly in South Yorkshire, but also in North Derbyshire and in the North East of England region where centres had joined the open recruitment. Although the majority of participants were recruited in the city of Sheffield where I am based, the input from participants from centres in surrounding areas helped to explore and compare views and experiences. The recruited participants were working in Sheffield (15), Rotherham (2), Barnsley (2), Middlesbrough (2) and Chesterfield (1). Participants from Barnsley (1) and Chesterfield (1) also had part of their other roles or practices in Sheffield.

Practitioners working in different locations may have developed services differently; therefore, I explored the possibility that there would be differences in practice and perhaps in local systems. I examined the data to explore differences that may be relevant to the interpretation of findings such as ways of working described by participants from different areas. Changes to ways of working were reported by participants in different geographical locations. These reflected the effect of national health policy changes for example in the merging of community contraceptive services with sexual health services, and change of working practice in midwifery services. There was some information emerging from interviews about how regional services for asylum seekers and refugees were not being supported in all areas, with some report of closing of services. Although this described situation was located in areas not covered by this study, it could affect the implications of the findings involving the provision of health services for asylum seekers and refugees in the wider UK context.

3.5.2.Semi-structured interviews

All interviews were carried out between January and August 2015. Interviews lasted between 25 and 50 minutes and were conducted face-to-face with the exception of three where physical distance meant it was not practical to meet therefore interviews were done on the telephone. The topic guide and prompts were applied to all interviews with flexibility and consideration of differences in the flow of communication, and to explore emerging themes. The topic guide evolved over time to explore emerging findings.

The introductory questions that asked participants to describe their roles and responsibilities, worked well as icebreakers as the narrative was about familiar aspects of their work and their context. The prompts aimed to obtain a more in-depth description of the setting and of the type of patients seen, and in the majority of cases, the conversation was fluid and did not need much prompting. In addition, description of roles provided useful information about the context and responsibilities of key workers and practitioners' involved in facilitating access and identifying system barriers.

The majority of interviews were held outside clinical working hours, either during days off work or during non-clinical sessions. Most sessions were set in clinicians' or key informants' offices in hospital, medical school, home or research offices; two participants lived together and were interviewed in the home after work; two interviews were undertaken in busy, noisy environments (a cafe and a restaurant), the recordings were affected by noise but the software used helped filter the conversation. In the occasions where I interviewed the practitioners in their offices after clinical work, the switch between seeing patients and talking about themselves was sometimes slow, in one occasion it was reported to have been influenced by tiredness at the end of a clinical practice session. The tree phone sessions progressed fluidly and the participants were keen to narrate their experience. In two occasions, participants on the phone were in work offices and in one occasion, the participant was at home. This last session at home had been re-arranged twice due to the participant last minute work requirements; the practitioner chose to have it while on day leave, as he was very keen to participate in the study to provide his shared cultural experience.

3.5.3. Descriptive indexing themes

The descriptive coding or indexing was used to break the data as described in the methods section and provided some insight into the type of data obtained. The following details are a summary of the data contained within the initial descriptive coding with examples.

Perception/insights about patients contained insights about communication and understanding in the clinical encounter; there were indicators that barriers exist in providing quality care for patients from different cultural background and for Chinese patients in particular

A practitioner described a difficulty in communication with a Chinese patient, which resolved by taking time to finally evaluate the practitioner understanding of the patient perception, albeit not in the area of chronic hepatitis B:

"… one patient last year, it took me a long time to realise that she didn't really see antibiotics in the same way as I saw the antibiotics. … it must have taken hours of sitting with her, talking with her to try and unravel what she was thinking and what I was thinking; I think it was time well spent because, until the penny dropped for me that she'd got a completely different idea about what this medicine was for, I couldn't understand why she was acting the way she was acting." P7

Other practitioners reported they experienced an easy consultation, for example, this male secondary care physician with 1 to 5 years experience describes how they behave in the consultation and interprets this as sign of engagement and understanding:

"I think the Chinese patients that I meet generally seem to be well informed and relatively… well educated, certainly that's my non-informed impression. They seem to like looking at results, they sometimes will write them down, they seem to like to follow results eagerly, but that helps reinforce that they are engaged and actively interested in their health condition, the progress of their health condition, and generally they're very polite, they're very willing to listen" P10

This particular indexing theme also included some general impressions about patients and also related to skills in transcultural care:

"Patients I can think of just as a generalisation, they tend to be less emotional or appear much more guarded. So and again it's only small numbers but you know less likely to ask questions or clarify." P9

Perception/insights about chronic hepatitis B indexed insights about the complexity of the information about chronic hepatitis B:

"I give them the leaflet in English but … I think it carries so much information I think I would have difficulty absorbing it all quite honestly,…" P11

Or how to explain the effects of the condition on patient's health:

"It's hard to actually help people to understand it in a pictorial way because it's all about relative risk … people don't want to know about relative risk they want to know about what's going to happen to them, they want to be given clear instructions about how to help themselves and their immediate family. They don't want grey risks…" P8

Perception/insights about service included lack of clarity about organizational issues, such as financial responsibility for patient care:

"Say I screened all our high risk groups and found we had 10 hidden in all the clinics… what happens if we refer them on? Will the department have to pay for the treatment or is it going to be taken on by primary care or ID [infectious diseases] that would make a difference. I don't think it would be the primary reason but it probably sway… [the decision to proceed]" P14

Perception/insights about service - Support for spoken language, contained both experiences of using different modes of interpretation, and advantages and disadvantages found with different approaches. Difficulties with equipment were also described among other issues.

"Slow, clunky, on examination how do you bring the phone when you are explaining what to do… lay on that, sit, you have to work out. So can you tell him that I'm going to ask him to do this, then I am going to ask him to do that … lung examination, rectal examination will be doing this all before you are there, because you are then 3 yards from the phone so you can't explain what you are doing" P12

Perception/insights about service - Supportive information (printed/online): participants described the need for correct information and the wish to have information to provide to patients.

"Probably, one of the things we could do is to look at some more written documentation. Just basic things, like this is what hepatitis is information leaflet and reinforcing the importance of going for the hospital appointment, and why is

important to go for them. But I am not too sure, I am not sure how literate a lot of them are." P1

Perception/insights about service - Professional support was informative about how practitioners dealt with specific problems in management of patients that required specific advice. Primary care practitioners ask for support from specialists of public health services.

"I have phoned up ID registrars if I need any more help or advice about things, but also the Health Protection Agency because I know there is always someone at the end of the line. I've never used them for Hep B itself but usually other things." P5

Perception/insights about policy and guidelines revealed uncertainty and lack of awareness.

"But there aren't any… I mean there's no trust wide policy I guess if someone presents in secondary care for any reason whether it's diabetes or chest pain, for high-risk groups. Is there a national policy?" P14

Indexing using theory models

This subsection contains examples of the descriptive indexing described in Table 3-3.

Indexing using Candidacy model

Navigation/ understanding included text where practitioners were aware of the difficulties of individuals in regards to accessing services.

"Often is on the second or third time you see them that you get more information from them. They are not upfront with what the problem is initially, but I wonder if that is because a lot of them that come here, you'll find that they either a friend of somebody that is already registered here. And they've come with another Chinese person that brought them to get them registered, but that is because so many are undocumented" P1

Adjudication/understanding and offer/understanding implies the practitioner mentions practice or experience related to adjudication of candidacy and offer of services.

"I cannot imagine that any of us would get an abnormal, at least in our practice, that any of us would get an abnormal hepatitis result and not do anything about it. I thought all of us would take some sort of action." P4

Ad-hoc descriptive indexing

The ad-hoc indexes were created because there were some themes that were considered important to investigate further and were not identifiable in the originally set descriptive indexing. These were indexed by the following terms: 'engaging with the community', 'entitlement', 'paternalism' and 'too much medicine'. Overall, these were considered descriptive codes and helped to become familiar with the data but provided a space to highlight meanings and help construct interpretive findings. I briefly describe these index codes here; the meanings constructed will be discussed in the next Chapter.

Engaging with community groups

A few participants from different professions mentioned community engagement as a way to address barriers, and although this could not address service barriers as such, it seems important to understand the meaning behind these expressions.

For example, a participant of Asian ethnicity suggested that religious centres could be a good way of delivering health promotion messages.

“Giving what you are trying to do actually is a health promotion exercise I think it needs to know what the community leaders are like in the Chinese community, for example… I’m a Buddhist, I’m from (non-Chinese Asian country) so we would go to temple, and in the Muslim community it would be the mosque, so I don’t know where would you go to promote the advice?” P16

These insights will be explored further in the next chapter under cross-cultural communication.

Entitlement

The decision to indexing this insight arose from the perceived emphasis that some practitioners working with underserved populations put on this subject. Entitlement was mentioned as an important piece to take in account when evaluating communication with patients, the emphasis being in the reassuring messages to give patients. Entitlement in this scenario may be understood as patient perception about not being entitled to the services on offer accompanied by feelings of apprehension. A practitioner working with asylum and refugee health services described her experience.

"A lot of them that come here with either a friend of somebody that is already registered here, and they are, not necessarily a relative, but somebody who has come to stay with somebody. They've come with another Chinese person that brought them to get them registered, but that is because as I said so many are illegal [meaning undocumented]" P1

This descriptive code raised a point that is discussed in the next chapter in terms of interaction between practitioners and patients around trust and how previous adverse experience could influence communication during the clinical encounter.

Paternalism

Paternalism contrasts with shared decision-making, and with patient involvement in their own health care (Charles et al., 1999). It implies that there is a hierarchy and the power lies in the professional to decide what information and medical advice is given. Paternalism is understood as a one-way interaction from the more informed or powerful to the less informed, that aims to make a decision with a minimum of information exchange (Charles et al., 1999).

Two practitioners working in different areas used this concept during interviews in relation with practitioner's role or practice. A primary care doctor explained how to approach requests from patients for a hepatitis B test.

"You can't say yes to everything but equally it's very difficult to be paternalistic and go I think you don't need this. Particularly with something like hepatitis because there is so much to do with lifestyle and previous experience and sexual experience that people find difficult to talk about." P9

In the area of medical education, a participant referred to a traditional definition of practical learning.

"People in medical school argue sometimes that medicine is an apprenticeship, but it has to be an intentional apprenticeship. You can't just say like some people say 'well you know in the old days you just follow your consultant around, and saw what your consultant did and you learnt that way', and they'll say and it didn't do them any harm. It was a very paternalistic approach, so again watching what your consultant does, doesn't mean it was the right thing that your consultant was doing." P17

Within medical training, shared decision-making had relatively recently been recommended for curriculums, in addition to problem solving, communication skills and reflectivity, aiming to change old ways of practice such as the paternalistic model (Frenk et al., 2010).

Too much medicine

The phrase "too much medicine" is taken from articles published in the British Medical Journal in early 2000's and also an editorial close to the time the interviews were undertaken. The publication expressed concerns about people being over-diagnosed for example with conditions that they may never develop. It also tried to address the problem of poly-pharmacy, meaning the taking of multiple pills daily for many year,) especially in older people (Glasziou et al., 2013). Two practitioners mentioned similar issues when describing how testing for hepatitis may be influenced by other issues of professional importance.

"Even the Association of Medical Royal Colleges have come up with a recent statement, which of course doctors are delighted hear, that doctors are over testing patients. There's still a lot people who will argue that older age is not a disease and yet, you know people are making old age a disease; and some people will say osteoporosis is a disease of the elderly, and that how can something be diseased when 90% of the population have that condition? What is normal and what is abnormal?" P17

The relevance of the descriptive findings for the study is discussed next.

3.5.4. Summary of descriptive findings

The study recruited 21 practitioners from different areas of the health service and from community with roles and experience that are relevant to the research question. The sample was restricted to two Northern England geographical health service areas namely South Yorkshire and North East. However, the strength of the study resides in the variety of views and experiences. These were from primary and secondary care, insights from non-clinical health promotion practitioners and from two community workers involved in facilitating access to health care provided by the NHS. Comparing and contrasting these insights, including views of practitioners that have shared cultural experience, aimed to develop an understanding of the social processes involved in providing health care for minority populations, in particular of Chinese ethnicity.

The descriptive indexing helped to identify data relevant to the research question. After becoming familiar with the data, conceptual themes started to emerge and this helped to narrow the data into factors that could potentially affect access. The narratives contained description of professional roles and insights into the uncertainty of practitioner's roles in facilitating access to health care. They helped identify internal and external factors influencing this role. These insights and interpretive findings are discussed in the next chapter.

4. Results

This chapter presents the interpretative findings and is structured to provide initially an overview of broad categories comprising the interpretive themes.

The themes are arranged around the role of practitioners in the domain of adjudicating candidacy and around addressing the health need of an individual by offering services such as testing or referral for treatment. These domains were discussed in the Background chapter in relation to the Candidacy Model for access to health care by vulnerable populations (Dixon-Woods et al., 2006).

The three overarching categories distinguished factors situated at different but interconnecting levels. Firstly, individual factors were defined as personal and professional values and motivations that inform and regulate the decision-making process. Secondly, factors related to the interaction of practitioners with individuals in the clinical encounter included power balance and transcultural communication and care. Finally, organizational factors included support provided for the role of the professional, and wider institutional factors such as funding and public or medical discourse that could influence the decision-making process.

4.1. Overview of categories and themes

Individual factors

This category refers to professional principles acting in carrying-out the work of practitioners and personal values present in the narratives that could influence decision-making.

Practitioners described personal and professional experiences related to their roles and provided insight into the self-regulation mechanisms that they use in practice. The themes included in this category are professional principles of good medical practice, trust, inclusion and the application of medical knowledge. Knowledge base and skills of practitioners are fundamental to deliver health care and personal values and professional principles guide practice and the approach to complex problems.

Clinician – patient interaction factors

This category includes factors identified within the clinical encounter, related to the interaction and communication between practitioners and patients. Themes in this category relate to the process of exchange of information necessary for shared decision-making, and included skills that practitioners develop aiming to achieve an effective interaction and communication. The interaction and communication related to chronic hepatitis B, and with individuals from a different cultural background revealed many uncertainties. In this section the interaction between practitioners and individuals of Chinese ethnicity was also explored further from the data provided by participants of shared cultural background.

Organizational factors

This category is defined as the institutional or organizational factors emerging as influential in the decision-making process. This category included the effect of local priorities for health care services, priorities in public health and the effect of national policies, funding, audits and guidelines, as well as the influence of general or professional discourse. The institutional framework and the support provided by the organization to deliver care are also included. Although these factors are more general and not always the responsibility of practitioners, they appeared repeatedly in practitioners' narratives as influencing their work and directly affecting communication and clinical decision-making.

Figure 4-1 - Overview of categories and themes

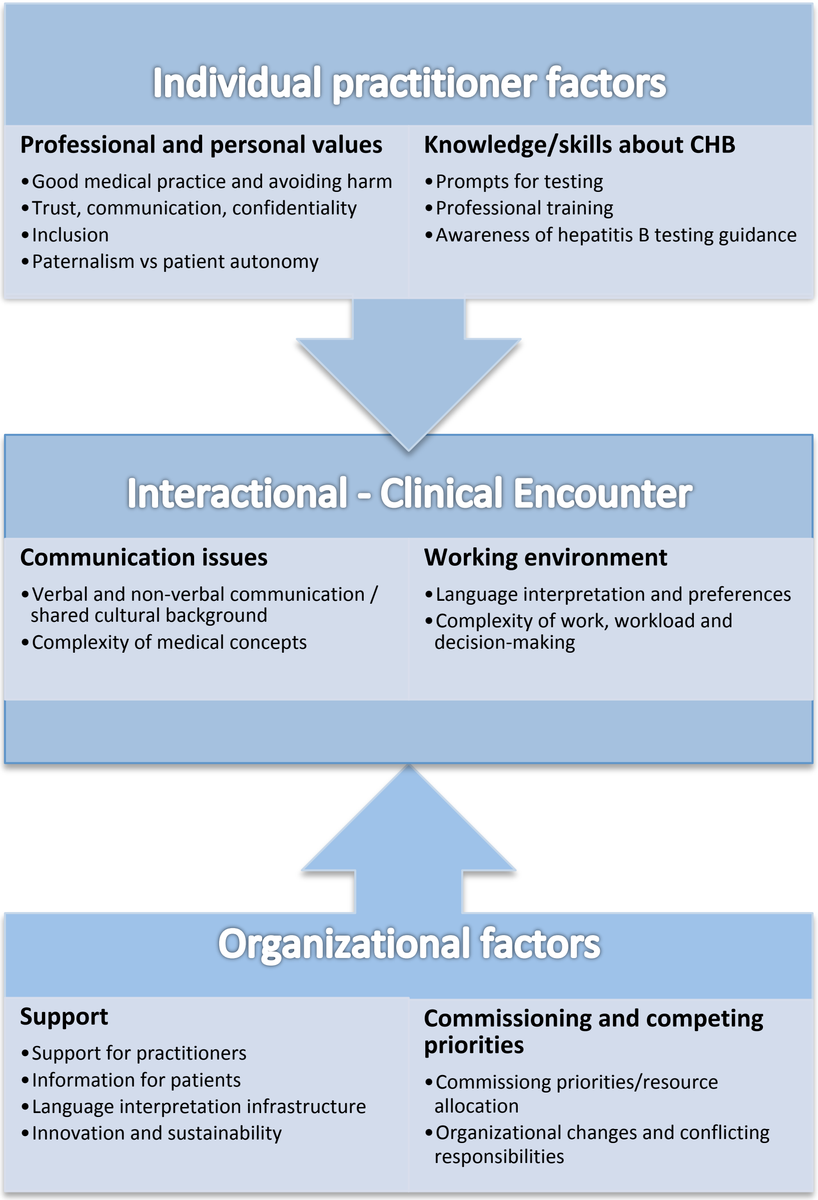

Figure 4-1 represents the main themes and subthemes. Although they are presented separately, these are related by either providing regulation (good medical practice, inclusion, trust), enhancing (support, interpreters) or hindering (knowledge, lack of support, poor infrastructure, structural racism) the domains of adjudication and offer as main functions of practitioners affecting access to health care.

Quotes and participants demographics

The participants quoted had different demographics, work setting and length of experience in their role. Participant (P) number is mentioned at the end of each quote and the number refers to Table 3-4 found in the descriptive findings section of Chapter 3.

To facilitate interpretation, the abbreviations inside the brackets clarify the settings and demographics as follows:

Setting: PC refers to primary care, SC to secondary care and Co refers to community.

Practitioner details:

Gender: M (male) and F (female).

Experience in years: <1, 1-5, 6-10 and >10.

Age group in years: <35, 35-49 and 50-64

Example a):

- **P2 (Co, F, 1-5, 35-49) –** This quote was from participant 2, who worked in a community setting, is female, had 1 to 5 years of experience in her role, and was aged between 35 and 49 years.

Example b):

- **P12 (PC, M, >10, 50-64)** – This quote was from participant 12, who worked in primary care, is male, had more than 10 years experience in his role, and was aged between 50 and 64 years.

4.2. Individual practitioner factors

Individual factors have a focus on the domains “adjudication”, that is the process of acknowledging the health need in relation to chronic hepatitis B, and “offer” of services such as testing or referral to specialists as part of the candidacy model (Dixon-Woods et al., 2006). These can be represented in two questions:

- What individual values and professional principles, experience, and knowledge are involved in the process of adjudication and offer?

- How do these factors affect recognition of risk and offering of testing for HBV; and, further on the pathway, referral to specialist hepatitis services?

4.2.1. Theme: professional and personal values

Practitioners were engaged in the decision to initiate or offer testing for HBV. The type of practitioners' work influenced this practice. In the UK, mainstream primary care services offered testing if it was required after a clinical abnormality or a risk assessment. In contrast, specialist primary care services such as those looking after refugee and asylum seeking individuals tested all patients following a screening protocol. Some secondary health services also tested all patients following either a national guideline or a departmental protocol. Examples were antenatal services and infectious diseases services. Most other secondary care services were testing depending on clinical assessment or specialist infection-control protocols.

A number of factors could be identified in the narrative that pointed out to the individual's professional thinking process. These processes had been studied in the literature as knowledge and practice; however, other factors such as personal and professional values had an important role in the process.

Professional values: good medical practice and avoiding harm

Prompts to test were influenced by professional motivations of good clinical practice. Many of the narratives had shown implicit awareness of these codes and other values. This example demonstrated that motivations could be to provide testing for individuals in a frame of good clinical practice if the practice is sporadic.

"I think at our practice if someone said - look, we'd like you to test any migrants that you come across and that qualify for this -, because we have so few, I don't

think we would mind doing that at all. I think we would probably just do it as part of good clinical practice." P4, (PC, M, 1-5, 35-49)

Another primary care practitioner reflected on how practitioners' lack of awareness could work against offering tests. Even if asked to do so, which deflects the principles of good clinical practice and shared decision-making principles.

"Sometimes the barrier to testing maybe that there's ignorance in the practitioners who have had contact with that patient. There may be some, both primary and secondary and tertiary care providers who when asked if they can do a test, refuse. I'd like to think that that's uncommon, but I'm sure it does happen. And if the medic or the nurse involved doesn't appreciate that there's a high prevalence of hepatitis in the Chinese community they might not realise the importance of doing a test, even when asked to do one. P9 (PC, F, 35-49, >10)

In secondary care, a hepatitis specialist raised the point that offers of testing may be missed without proactive practice in cases with fewer patients at risk.

"The problem is people [practitioners] who work in a low prevalence setting where they're only going to see a handful of cases at best within a year. How do you ensure they're not missing those specific cases when they're not actively thinking about it?" P10 (SC, M, 1-5, 35-49)

A secondary care practitioner who was not involved in habitually testing agreed that his main work took priority and testing for hepatitis B was not in his focus.

"I think it sounds like it's a worthwhile thing to do, when you mention we should be screening people and we're not, I'm asking myself - why am I not doing it? Probably it's that I am in the midst of trying to sort out CKD or dialysis and it's not on my radar." P14 (SC, M, 50-64, >10)

One major Hippocratic principle of practice is *"first do no-harm".* Primary care practitioners influenced by professional discussions about creating unnecessary diagnosis may not favour testing, even if their perceived risk of harm was not correct. A participant described his thoughts when talking about chronic viral hepatitis (including hepatitis B and C).

"…we have a choice of generating new illness by making a diagnosis that didn't have to be made for 10, 15, 20 years, having a disease that we can't treat." P12 (PC, M, >10, 50-64)

Good clinical practice is a main principle regulating the medical care professions, and is considered an essential code of practice published by the General Medical Council UK (General Medical Council, 2013). This code of practice highlights that it is essential for good medical practice to ensure quality of care, safety, respect, confidentiality, honesty and integrity. These principles regulate and support the application of clinical skills and scientific knowledge. In this examples, reflectivity of practitioners revealed how some of these principles worked in practice.

Trust, communication and confidentiality

A community key informant who had previously been involved in a study of access to services also described how confidence in the health system failed to be built by clinicians. The participant qualified the findings of the previous study as mistrust in the system; this was based in patients' reporting of gaps in communication from practitioners.

"There is lack of trust, having to see the GP many times, kept in the dark about their situation in hospital, what is happening with them. Nurses and doctors see them [patients] and they don't verbally communicate and tell them what's happening, so they thought that they were not getting a good service anyway, there is mistrust in the system." P19 (Co, M, >10, 35-49)

This quote also reflected the theme of communication during the clinical encounter, supporting the concept that building of confidence and trust, and effective communication are intrinsically related (General Medical Council, 2013).

Maintaining trust is an important value to achieve in order to offer appropriate and effective health care, and one of the principles of Good Medical Practice (General Medical Council, 2013). In this principle, physicians are expected to build trust with patients by showing respect and treating fairly and without discrimination. This principle explains that to be acting with honesty and integrity includes ensuring that information given is correct and no information is left out, among other recommendations.

Confidentiality appeared in the data when a participant described patient attitudes towards practitioners that could influence communication. Some narratives pointed to patients' apprehension towards services in general; for example, having a misunderstanding of the power health services may have on liberties. This practitioner mentioned patients registering in the asylum health practice and highlighted the role practitioners have in communicating confidentiality and managing fears.

"The only barrier I can think is that they think that the health service is linked to immigration …and as soon as you can allay that fear… I don't know about the Chinese but in many African countries the health professionals do have links with the government and that is what are they frightened of." P1 (PC, F, 6-10, 50-64)

This was an example of lack of trust in the health system that could stop patients accessing services or expressing their needs. The lack of trust could be addressed by the practitioner with assurances of confidentiality to improve communication that could help guide clinical decision-making.

The same participant mentioned some Chinese patients would take longer to communicate and they needed more prompting to discuss their health and interpreted this as time needed to build trust.

"I think particularly with some of the Chinese they are not as forthcoming as some of the Africans… I think you have to explain what you are doing and, it sometimes it takes the second or third time you see them that they are more trusting with you." P1

Trust, communication and confidentiality were interconnected in different ways in these narratives, showing overlapping effects and concerns. Other examples are included in the category Clinical Encounter and the Clinician-Patient interaction.

Other values and principles

Values and principles that were identified in the narratives can influence an effective interaction during the clinical encounter. These were inclusion and paternalism versus patient autonomy.

Inclusion

This value referred to the ability of providing equity in services to everyone, including underserved populations and those that suffer discrimination. Inclusion also referred to the participation of all sections of populations, for example a participant of Asian Chinese ethnicity mentioned reaching out to a community centre, but included a warning about inclusiveness of these groups.

"I would probably engage as you have done with the Chinese community... get the community centre and… I guess you've also got to be careful that the centre represents the community… because sometimes you find in some communities the centres are quite fractured so the centre ropes in half the community and the other half is disenfranchised" P14 (SC, M, 50-64, >10)

The participant that had spoken about the lack of communication from providers and distrust in services by patients, expanded on the description of inequality reported in his study, which was carried out in a different population.

"Another thing - many of them think that there is prejudice, as soon as they think that these people are migrants, think [that] they are not getting the care that they deserve; they think that other people, for example white people are treated differently." P19 (Co, M, >10, 35-49)

Discrimination on the basis of a diagnosis could be an experience patients suffered abroad, for example this community key informant described that a child was turned away from kindergarten in China after a blood test proved she had hepatitis B.

"I just came across a case. It was a Chinese girl; she was born in this country, so the family had a plan to stay with her relatives in China. Then her guardian in 2008 went to register her in a kindergarten in a large city in China. The kindergarten did a blood test. I don't know why they did a blood test. And she was told she's got Hep B and she was turned away. She cannot register in the kindergarten in China. I accompanied the girl and her guardian to see the GP this morning, and she was referred for a blood test. I don't know whether you know that in China, may be discrimination, even the kindergartens, they turn you away." P20 (Co, M, >10, 50-64)

This and other examples that emerged from the community arm focus groups reflected experiences of system discrimination in China for having hepatitis B.

Health promotion participants working in community settings also had roles that involved working out how to engage with underserved populations. A health promotion participant highlighted the importance of addressing groups of different cultural background.

"We recognize that different people have different needs, so what would work for MSM [men who have sex with men] and the language we use and the way that we target people in terms of information probably would not be the same information or language that we use for Black Africans" P18 (SC, M, 50-64, >10)

Health promotion could be considered as a role of community services or local authorities, but it can be embedded in practitioners' work, for example, as part of midwives roles in promoting healthy pregnancy and child early life. A midwife revealed awareness of the diversity that exists in her area of work when encouraging mothers to come out to visit the service where they can meet other mothers.

"You've got at least probably about twenty-two, twenty-four different languages in the city, which are the patient's first language. And it's just again being aware of the culture. And when you are trying to get them to come out to see us, is it within their culture to come out? Or do they say no, our culture says to stay in for forty days. So you have got to respect that obviously." P2 (Co, F, 1-5, 35-49)

In these examples, narratives represented inclusion from different perspectives that contemplate different needs from different populations. There was awareness of mistrust in the system whether this arose from previous experience in this country or in individuals' country of origin, and awareness that working with community organizations may not service the entire group. In addition, modifying ways of working by practitioners and using targeted health promotion information could be a response to addressing individual groups' needs.

Inclusion could be also seen in an example of innovation. When asked how did the asylum health service started, a participant described the systematic barriers encountered by migrants during the dispersal policies of the late 1990s.

"So you had groups of people from all over world just sent to us and of course there was no question of interpreters in those days and if they found us they were lucky, they were new in the town. There were access issues, interpreting issues,

our education issues, we had no idea on how to help them. Then there was a good article from one of the doctors up in Glasgow from the Medical Foundation for the care victims of torture; it is now Freedom from Torture. He wrote a very good article to say how to help people with problems from moved asylum seekers who have been tortured; that's a subgroup of the overall lot, but even so, it was a very useful article indeed, and that's what stimulated the need in my mind to provide a better service" P11 (F, PC, >10, 50-64)

There were many more expressions related to the awareness of inclusion mostly related to populations of different cultures and ethnicity. The overall conclusion when examining the transcripts was that the concerns participants had about difficulties individuals experience due to lack of support were more difficult to address in a context of competing priorities as mentioned in the following quote by a primary care practitioner.

"Things have changed dramatically across the country. There was a practice (asylum and refugee health) in [large regional city] which, was open for years and the PCT (old system of Primary Care Trust) just said we can't support it anymore and so now they don't have a separate service. The service in [smaller regional city] was also stopped and I know that other practices round the country are working on a salaried service basis." P11 (F, PC, >10, 50-64)

This is discussed further in system related factors under competing priorities.

Paternalism versus patient autonomy

A primary care participant suggested that if a patient requested to be tested for HBV she would consider testing after confirming what the patient's worries were. The practitioner also expressed that denying someone a test about a condition that concerns them would not be in the patient best interest, as it could be influenced by stigma.

"It's a fine line to tread isn't it? You can't say yes to everything but equally it's very difficult to be paternalistic and go I think you don't need this… Particularly with something like hepatitis because you know there's so much to do with lifestyle and previous experience and sexual experience that people find difficult to talk about." P9 (PC, F, 35-49, >10)

When decision-making was explored in the context of patients' choice in the narratives, it was noticed that there were missed opportunities to address shared decision-making. When the same practitioner was asked whether patients were consulted before ordering hepatitis B tests, it was clear this was not the norm.

"*I don't always and actually just the fact that you've asked me makes me wonder whether I should, but often I don't."* P9

A secondary care participant explained how to treat patients in a respectful manner but also to be aware of how practitioners' attitudes could increase inequities.

"One of the basic things about respect is putting yourself in that person's shoes, treating people how you would like to be treated yourself. You might be with someone who is articulate, educated and therefore if they feel something is not right they can say so, but the other person feels 'this doctor who spoke to me like a god and I'm down here' and they can't." P17 (SC, M, 50-64, >10)

Paternalistic approach was also mentioned in the context of medical training. The same participant above when describing how to use interpreters brought up the issue of a paternalistic approach to medical training. In this case, he was describing how a student or junior doctor would learn by just watching a senior doctor use interpreters.

"Learning from watching someone was a very paternalistic approach, watching what your consultant does, doesn't mean it was the right thing that your consultant was doing." P17

The description of paternalism in these quotes suggested it continued to be present in health care services, sometimes interfering with the standard of patient choice and autonomy, and influencing medical education.

A community key informant separated a situation of patient autonomy when deciding not to attend services from a lack of awareness that chronic hepatitis B could be treated. In particular, acknowledging that some people have been neglected by the health service in relation to the availability of treatment.

"There's a group of people, Chinese people, who know they are carrier of Hep B, but they're not doing anything about it. Now firstly, you've got to divide this group of people. If you're talking about say someone who has been told by the doctor 25 years ago, you got Hep B, then nothing happens now, they will still live happily without going through the monitoring. These are the people that have been neglected by the system, and they haven't had the awareness to go and make it right. Another group who might say 'I know it's there, I know I've got Hep

B, but I just don't bother, it's not affecting my life right now'." P20 (Co, M, >10, 50-64)

The group described first in this quote represented the motivation for this study. Although it is known a large proportion of people at risk have not been tested, part of the population that was diagnosed when the condition could not be treated, were still not accessing treatment. The key informant clearly pointed out the barrier is in the system.

An example of the expression of patient autonomy was shown when a participant described a patient declining treatment during pregnancy. Although the aim was to prevent transmission of HBV, the choice was based in the thought that medications taken by the mother could cause harm to the unborn baby. This particular narrative revealed a conflict between the professional offer of treatment and the patient's decision not to take treatment. The participant's words reflected this conflict. At first, he was critical of the patient's position. But in trying to understand the patient's point of view, he adopted a more balanced position. He contemplated the reasoning behind declining offer of treatment, without losing view of the clinician's viewpoint.

"Some will sometimes have very their own fixed ideas… I don't try to push on or impress upon people that actually you must have this treatment but I try and engage them with the options. For example, some pregnant Chinese ladies, some of them are quite 'anti' taking medication, with the attitude of 'first do no harm' I suppose, and will not take a drug that could potentially harm their baby. I think

they appreciate that there’s a higher risk of transmission yet on the balance of risk/benefit they felt it was more risky than beneficial.” P10 (SC, M, 1-5, 35-49)

Paternalism is a style of relationship that neglects individual choice (Charles et al., 1999). There is evidence of paternalistic thinking and practice in many narratives from secondary care, where advice is given without having better insight into the patient context and preferences. Primary care participants had more awareness of the need to appreciate contextual needs and deal with patients’ requests. Patient autonomy in regards to diagnosis and treatment preferences can at times be overlooked or be challenging for clinicians.

To ensure that decisions are made with the patient, requires that all information is communicated and understood. All aspects of management and implications of any choice need to be discussed. For the practitioner this may require clarity of values and acceptance of individual choices. In the case of chronic hepatitis B, implies understanding the implications and complexity of the condition, and considering the impact of a diagnosis on the patients’ life.

4.2.2. Theme: medical knowledge associated to chronic hepatitis B risk

Among individual factors, it is important to reflect on skills and knowledge about chronic hepatitis B that emerged from the interviews, as this is a predominant theme in the literature of practitioners. The rationale behind testing for hepatitis B in primary care involves thinking if testing would be appropriate when individuals present to the service for other reasons. The findings indicate that appropriateness is mostly decided by using in the first instance a medical knowledge base, although other intersectional factors also emerge.

Prompts for testing

The decision pathways were complex and depended not only of medical knowledge but also of awareness of epidemiology, protocols, and as previously discussed, principles and values. A practitioner described her thought process when asked in what circumstances they would consider a test for hepatitis B and when they would not. Here the medical context of liver health guided the rationale.

"We don't test everybody but we've got a pretty low threshold. We've had them present unwell. Another reason for doing it is we have done tests and they have abnormal LFTs, but not tested for hepatitis then I say I will do it. It depends on what is abnormal in the LFTs. If they have abnormal LFTs, they are overweight, and they have type 2 diabetes, I'm thinking well non-alcoholic [steatohepatitis/fatty liver]. *Then I'd probably scan first before doing a hepatitis screen."* P9 (PC, F, >10, 35-49)

Other examples of assessing factors associated with HBV that are at the forefront of participants' thinking included acknowledgment of behaviour that increases the risk of infection. A practitioner mentioned a history of use of intravenous illicit drugs or of commercial sex. He confirmed that none of the liver abnormalities that were followed up by this rationale revealed chronic hepatitis B in a cohort that was mostly white and working class, upholding that fatty liver and alcohol were the main culprits.

"…He drinks a bit too much. The LFTs come back a bit abnormal. You know it is probably the alcohol, fatty liver, nothing more than that... that's the commonest reason why we do it. Very occasionally you will get somebody who comes in with a slightly odd history of perhaps feeling generally unwell, the tests may show abnormal liver tests and you do a non-invasive liver screen. I think I have had one or two patients who have had slightly risky behaviour; that they have admitted to taking drugs in the past or having sex with prostitutes. And I have explained to them I think we need to do a check for HIV and other tests. I have never had any of those come back positive at all." P4 (PC, M, 1-5, 35-49)

Another participant did not link the family history of a patient that was diagnosed with hepatitis B with the likelihood of vertical transmission. This was not at the forefront of the practitioner's thinking, perhaps confounded with the patient report of having tested previously.

"…it turned out that he had Hepatitis B which initially he was very shocked about. And after a few consultations, it turned out that he thought that he was negative when he was tested before. And then later on came up with the story about how

actually he might have been positive because his brother was positive." P5 (PC, F, 6-10, 35-49)

When questioned about what would prompt a HBV test, the same practitioner omits to name family history or high prevalence in country of origin that may point to vertical transmission and testing despite normal liver function test (LFT) results.

"Yes, usually the biggest thing really is abnormal LFTs, it's part of our work sort of non-invasive liver screen doing Hep B, Hep C. Any patients who are drug users or have been drug users. Patients of ours, some with mental health, some with no mental health problems, who we know are promiscuous. I can't think who else I would consider testing." P5 (PC, F, 6-10, 35-49)

As presented in the background chapter, in the UK the more common forms of transmission are horizontally between adults during intercourse or sharing sharp objects. Vertical transmission at birth is rare, and this may be the reason for the lack of awareness of epidemiology in relation to relatives.

In secondary care, local protocols helped guide specialist practitioners to maintain infection control during management of medical conditions, but there was no proactive aim to diagnose hepatitis B in early stages if the patient was from a high prevalence area.

A participant described testing for HBV as it was indicated in his specialist practice. Although he first described a blanket policy of testing for blood born viruses, he then explained that this was only done when treatment with dialysis was being considered. He expressed uncertainty about testing without these criteria.

"Everyone gets screened, that's regardless, so that's like a blanket policy for dialysis, pre-dialysis for hep B, hep C, HIV I think. For patients not needing dialysis we may screen if we think that it's related to kidney disease so for example hep B, hep C, HIV can give you also glomerulonephritis and if there is uncertainty or we do a biopsy and find that looks like hep C, then we need to test. I guess for diagnostic reasons we might, but if they had CKD without any proteinuria or any significant glomerular disease I'm not sure that we have a policy to screen." P14 (SC, M, >10, 50-64)

In this study, practitioners that needed to make a decision about whether to test did not consider the possibility of hepatitis B infection without liver tests abnormalities or without history of behavioural risks in high prevalence groups.

The narratives also showed that common preventive protocols were applied in primary care to healthy people who fulfilled certain criteria. For example, cardiovascular disease assessments involved performing some blood tests aiming to pre-empt complications by detecting abnormalities early in people over certain age. If the results showed abnormal liver tests, further tests including hepatitis B were requested to elucidate the cause of abnormalities. Epidemiological risk and vertical acquisition were rarely at the forefront of the decision-making process.

Professional training

Practitioners were asked about their training as students, trainees or as trainers for others in regards to chronic hepatitis B. The responses showed participants could not identify where the teaching about chronic hepatitis B fitted in the program. A primary care practitioner described her medical training as very good as she had training in general internal medicine before becoming a GP. However, she could not remember sufficient clinical teaching focusing on hepatitis B and points out it is only mentioned it as part of a differential diagnosis.

"I'm trying to think if we did any infectious diseases. I must have done at some point but I think it was only there as part of a differential diagnosis of an abnormality, it was usually there as part of a list related to various symptoms. It's difficult to say whether I had enough knowledge because you've got to know everything." P9 (PC, F, >10, 35-49)

Another GP involved in the training of doctors did also reflect that the training on hepatitis B was given under gastrointestinal disorders and sexual health but in both cases, it was listed as one cause of abnormality or liver tests or sexual transmission.

"If I'm honest I suspect we don't tend to cover Hepatitis B or C in a lot of detail. It is definitely part of the GP curriculum. I think it comes under gastro-intestinal disorders. I think it is definitely under that part rather than sexual health, although it is also there [in sexual health]. I think when we've done it in the past it's probably been more so as part of a tutorial or a session on liver problems and

abnormal LFTs rather than on Hepatitis B or C in itself. That might be because at least in [city] we don’t come across it as much.” P4 (PC, M, 1-5, 35-49)

Participants tell us there is a paucity of training about the condition; it was not taught independently as a topic but mentioned only in a list of diagnosis to take in account in sexual transmission or abnormalities of the liver.

Awareness of hepatitis B and impact of national guidance

The interviews presented an opportunity for participants to clarify their doubts about the condition. The information sheet explained the reasons for the study, but questions still emerged at times when clinicians reflected on the relevance of chronic hepatitis B in their practice. Questions around guidelines or protocols demonstrated that specialists in secondary care only knew about testing recommendations in their speciality. Examples included before immunosuppression or dialysis, and the regular testing performed in antenatal, sexual health and asylum and refugee services. Only an infectious diseases participant mentioned national guidelines that encouraged offering testing to people migrating from areas where chronic hepatitis B is prevalent.

“A lot of it is about education, not just with the patients and the high prevalence groups of patients, but also that professionals most likely to interact with those patients in their community and in primary care certainly know of the need to test. I mean its part of the NICE hepatitis B and C testing guidelines that people with higher or intermediate risk areas are tested, but then is how they are implemented. How are those guidelines embedded into normal practice?” P10 (SC, M, 1-5, 35-49)

The participant questioned the difficulty of implementing national guidelines; this was consistent with published data that show these had not had an impact in testing people at risk (Evlampidou et al., 2016).

Increasing relevance has been given to undiagnosed viral hepatitis causing chronic liver disease both worldwide and in the UK, (World Health Organization, 2013; Williams et al., 2014; Locarnini et al., 2015). Therefore, an increasing number of recommendations from international and national bodies, and campaigns to raise awareness have proliferated. However, primary or secondary practitioners' awareness was related to previous experience as explained by this participant.

"I think that it depends on what your experience is. If you do not come across many people with Hepatitis B, if you do not have any Chinese patients, if you do not have any Slovak-Roma patients, if you do not have many people who use IV drugs, you do not realise what an impact it has. And, you just do not come across the illness. So you don't understand long-term problems with it, whereas if you are dealing with it on a more regular basis, it's going to be more relevant." P9 (PC, F, >10, 35-49)

This participant had experience in advising commissioners and had mentioned the Liver Strategy (Williams et al., 2014) explaining the difficulty found when deciding whether to fund an enhanced local testing programme. These quotes are discussed in the organizational factors section.

The next section explores factors originating in the interaction between practitioner and patient.

4.3. Clinical encounter and the clinician – patient interaction

The clinical encounter is the space where the reason for needing health care is addressed and a core skill for clinicians (Like et al., 1987). Effective communication during the encounter requires two-way understanding of priorities and reasons (Joseph-Williams, Edwards, et al., 2014). Medical concepts are sometimes difficult to discuss, and understanding the impact of the diagnosis in people's lives by practitioners require particular skills (Légaré et al., 2008). Identifying what factors act during the interaction in the clinical encounter could provide information about barriers pertinent to practitioners. The concepts previously mentioned related to cultural sensitivity and humility, and the shared decision-making model, are relevant here.

4.3.1. Theme: Communication skills

Participants' narratives offered multiple examples of experience with communication. These experiences included description of verbal and non-verbal information exchange during the encounter with patients and the challenges this presents, or the skill practitioners may use in enhancing communication in the clinical encounter based on theoretical models of consultations. In most narratives, there were insights about barriers, highlighting the complexity and the awareness of practitioners about achieving effective communication. Many of the experiences described by participants were related to adherence to protocols and to personal interpretation of patient satisfaction rather than an exploration about consensus achieved during the consultation. However, the opinions about the need for communicating well and the need for training were clearly stated.

"The communication skills training I think should be wide reaching to every one including the consultants because you have poor communication skills as a consultant no matter how good you are up there in your brain still you will not be able to fulfil the needs of the patient" P23 (PC, M, >10, 35-49)

Another primary care practitioner described one of the models used in consultation that helped manage the understanding by interpreters and patients and acted as a general tool in communication.

"[I ask] – Can you just tell me what you understand by what I said? So chunking and chopping sentences as in the Calgary-Cambridge model that we

taught this to students years ago, and it works very well in practice, it's not just an academic method." P11 (PC, F, >10, 50-64)

The following subthemes describe how expressions in different languages may have different meanings and cause misunderstandings, due to practitioner preconceptions or cultural and linguistic conventions. In addition, it may be difficult to make medical language meaningful to inform shared decision-making.

Verbal and non-verbal communication and shared cultural background

This study was seeking to provide views from participants of shared cultural background and compared them to experiences of participants of non-shared cultural background. Practitioners were aware of the difficulties of cross-cultural communication. One white British participant working with underserved populations in community settings, warned about making assumptions about patient's response when communicating with a non-English speaker.

"Not surprisingly, if someone is coming from quite a different culture, then it is very easy when the patient sort of says yes and nods [to assume] *that they actually understand what you are on about…"* P7 (SC, M, >10, 50-64)

This practitioner also explained his interpretation of why this may happen with a person of Chinese ethnicity, with a culture that is perceived as polite and compliant.

"And because culturally I think they (Chinese patients) like to be very courteous therefore they are perhaps more likely to tell you what you want to hear because that's part of courtesy" P7

The issue of generalization was seen here. Although in some narratives there was awareness about the danger of generalization by some participants who warned about this, other participants, being unaware, generalized.

"They tend to accept everything you say, they do not question" P16 (SC, M, 50-64, >10)

On the same topic, a participant of Chinese ethnicity gave a similar opinion of this phenomenon by comparing the process with questions that elicit habitual responses in mainstream culture. In addition, he adds a cultural attitude that could compound a lack of response and described his strategy to bypass this.

"I think a direct question to say to the patient how are you like you say to an English person*, won't elicit much because, the right answer is "I'm fine"; if I said to you – terrible, you'd just look shocked and think what do I do next, – it's conventions, and they're sorry to bother the doctor, [did] you know?. So I think sometimes it's helpful to get more information from the wife or the relatives."* P14 (SC, M, >10, 50-64)

While following-up a patient in the community and monitoring treatment (unrelated to chronic hepatitis B), the previous participant who talked about assumptions, described a particular misunderstanding with a woman of Chinese ethnicity based on different interpretation of the purpose of treatment. This required long discussions with the patient for the practitioner to understand it.

"I had explained to her on a few occasions what I thought the medicine was doing but she got to a different belief system and it took an awful long time to agree and think 'we are talking the same language here'. It must have taken

hours of sitting with her, talking with her to try and unravel what she was thinking. It was time well spent because, until the penny dropped for me that she'd got a completely different idea about what this medicine was for, I couldn't understand why she was acting the way she was acting." P7 (SC, M, >10, 50-64)

Another participant of non-concordant ethnicity but extensive experience with patients of Chinese ethnicity mentions in an example how understanding the patient's context is important to guide clinical work even in a short clinic consultation providing an example unrelated to chronic hepatitis B.

"To me what somebody does with the rest of their life makes a big impact on their health. Of the Chinese patients I used to see [I remember] a woman in her 80s and knowing what she did, who she saw when she went to the community centre, what she tried to do there, how her disabilities affected her participation in groups then I could actually begin to help her deal with her arthritis and pain and everything. I was working with an understanding of what family she had, what context she had, what she tried to do, where her support systems were. Blind to that, you become an A&E doctor by default, without any of the technology to support that, it becomes a very minimalist understanding of the patient" P12 (PC, M, >10, 50-64)

Many professionals of non-concordant culture reported no difficulties in communication with people of Chinese ethnicity. This was either due to English language fluency or to unproblematic, rapid and engaged consultations, perhaps lacking the exploration of context. Patients of Chinese background were described as polite, always attending appointments, self-caring, engaged. The barriers acting in this situation could be more difficult to identify than with populations that express antisocial behaviour as mentioned by one participant. Her own perception and thoughts revealed beliefs consistent with the "model minority' stereotype of people identified as Chinese (Lee et al., 2009; Tendulkar et al., 2012), although noticing that this could also lead to inequalities.

"So my feeling is, with the Chinese community you do not see much anti-social behaviour. I think they probably do keep themselves to themselves. Again, I do not know, that is just my perception of it. They are quiet, self-contained group it seems to me. So because they have not upset people their needs are not immediately heard" P9 (PC, F, >10, 35-49) The following descriptions and quotes all refer to the same participant of Chinese cultural background. He warned about making assumptions that if the individual did not present problems in the consultation these do not exist, as these could take some prompting to uncover.

"…whether or not it is the perception that they are much easier because they don't have any problems so they [the doctors] think that you [the patient] are more compliant but the reality is if you scratch the surface a bit more, then you open the floodgates." P23 (PC, M, >10, 35-49)

According to this participant, if patients were worried about hepatitis B, they may point out to indirect symptoms or signs, rather than speak a direct expression of their worry.

"…they wouldn't tell you that I'm concerned about hepatitis B, or C or A; they will find direct questioning an alien concept. They'll say… doctor I've got pain, I'm

really worried about my pain on my tummy, my family tells me that I go a bit yellow sometimes so those are the hidden cues…" P23

He contributed to the above by explaining that indirect communication in expressing health issues in lower socio economic group could be misinterpreted and is frustrating for the individual seeking care.

"…there are other cues because the way they look when they're worried they try to bring friends and they will show a very miserable looking face, and keep sighing and things like that and these sometimes get misinterpreted by the English doctors as depressed but the reality is not actually that …it is because how they've been brought up, and the concern becomes a frustration to them and they feel that they've been let down" P23

He said that it is necessary to look for non-verbal cues to understand the patient difficulties. In the case he experienced, it was necessary to explore signs of depression in a different way because it is a stigmatized condition.

"… In the Chinese population, you need to look at how they burn out. When they become tired and over burden, you look for hidden cues but they wouldn't tell you that I'm depressed, even though they may be entitled to, they wouldn't tend to present to me with depression because it is a taboo subject because to be depressed is that you're weak in some way" P23

He warned that this is a way of communicating more easily found in people of reduced economic and educational means but may not be true of more educated groups.

"…the main Chinese population that comes here as economic migrant and also the lower social economic classes tell you that… but I wouldn't say that its everyone because I know some of the Chinese university students can be totally different…" P23

Although many of these insights cannot be generalized, it may be helpful for practitioners to be aware of the pitfalls in interpreting patient engagement or satisfaction by assessing expressions based in their own cultural interpretations. The narratives described complexities and inside-group diversity in people of Chinese ethnicity. Generalization of needed communication skills was not possible, but awareness that such difficulties exist could help the interaction. The same primary care participant had thought about the need to enhance training in consultation skills.

"…so one of the things that I actually am very, very interested is how to assess and how to make sure the patient's hidden agenda and cues have been met. Now a lot of this is not an overnight exercise even though you get some in general practice training it's not really that sufficient. I learnt lot of that by enrolling in training like consultation skills… particular techniques like reflect questioning. You can use it in every culture including the Chinese culture that will also respond to that because a majority of the time they feel that the doctor is being a parent directive…" P23

The previous quotes provided clarification for data that had emerged in previous interviews. The practitioner insights also coincided with the insights of the previous participant of concordant cultural background that had expressed the option to communicate with other members of the family or friends to strengthen the understanding of the patient.

In addition, the community key informant of shared cultural background expressed the view that many aspects in Chinese culture are similar to those in English culture.

“… I can tell you the cultural difference between the Chinese community and the mainstream society is much less than the same issue with other communities. I’ll tell you why. Because for the Chinese community, there is no dominant religious element, which actually affects our way of thinking, the way people… say people dying, and all that, how we dress, how we eat. You will find the Chinese community is very non-religious in many ways. There’s a significant percentage of Christianity and Buddhist or whatever. But in terms of a certain religion that’s affecting the life, it’s a very, very minimal factor of the community.” P20 (Co, M, >10, 50-64)

These concordant cultural views highlighted differences and similarities in communication that could be overlooked. These narratives described barriers of communication that could be potentially applicable to other groups. The unifying factor could be seen as assumptions about individuals. The assumptions created barriers of communication, in turn creating clinical risks such as misdiagnosis. The narratives show misreading of culturally accepted behaviour of some Chinese patients by practitioners of non-shared cultural background. This could be related to the bias of the practitioner towards his own cultural background or towards main stream culture, and could represent a barrier to understanding the needs of the individual (Smith et al., 2007). In addition, the narratives mainly described conveying information from practitioner to patient. Exploring information flowing from patients to practitioners was only mentioned by primary care practitioners who talked about understanding patients' context and the impact of a diagnosis.

Complexity of discussing medical concepts

Condensing information about chronic hepatitis B may be challenging (Wallace et al., 2011). Practitioners expressed concerns that medical terminology could be difficult to understand or to translate in other languages. The implications of a condition such as chronic hepatitis B were difficult to explain, even in the same language, to help make it clear to the individual seeking care. In addition, understanding the context of the individual and understanding the implications for people's lives was important in medical communication. A number of participants described these issues in different contexts.

When enquiring about patients' of Chinese cultural background a midwife explained that interpreters are important when medical language is used, missing the importance of ensuring overall good communication.

"…we probably need to be fair with the half of Chinese women that need interpreters, just to be sure that you were getting the right medical terminology across to them." P6 (SC, F, 1-5, 50-64)

Although a participant of shared cultural background revealed that interpreting basic information around the hepatitis B virus can act as a barrier for recognising the condition. This participant explained that in general, Chinese patients are aware of chronic hepatitis B, but it is important to use the correct terms in their language for it to make sense.

"… in mandarin hepatitis B is called (B xíng gānyán) which means B type inflammation of your liver, (gān) is liver, (yán) is inflammation, (B xíng) B type; so if you say it like that, they will know immediately, they know it but it's how you translate that and it's got to be 'that' word. As soon as you say it then the penny drops" P23 (PC, M, >10, 35-49)

Wallace et al. (2011) described that information about hepatitis B is complex and not easily simplified. A practitioner described the difficulties of caring for individuals affected by chronic hepatitis B. Decision-making can be compromised if the concepts are not meaningful to the person affected that needs to use that information to share a decision with the practitioner.

"…particularly if you're then asking them to try and make decisions and I would obviously try not to force people to make decisions when they've just been given a massive amount of new information. Sometimes if you're seeing somebody for a follow up [consultation], it's easy to assume that they've been given the information and they have understood all of this information … " P8 (SC, F, <1, 35-49)

In this study, medical information was thought to be difficult to discuss in any language. A relevant issue was the understanding of the impact conditions could have on an individual's life. Practitioners were aware of difficulties in communicating the relevance of medical knowledge especially in conditions where the impact in people's lives is not felt directly or may take time to develop. Interpreters provided valuable service, were generally knowledgeable, and participants appreciated this. However, participants were aware of the difficulty in knowing whether the interpretation reflected the intended information. This theme is also included in the next section around working environment. Finally, a practitioner proficient in Chinese languages was aware that if the concept of hepatitis B was not correctly conveyed patients might not be made aware of the purpose of testing or the condition discussed.

4.3.2. Theme: Working environment within the clinical encounter

The clinical encounter for non-urgent conditions could be seen as a bidirectional exchange of information between practitioners and individual patients to reach an appropriate and desirable decision (Charles et al., 2006). However, factors outside the encounter may act on this exchange of information and influence the decision-making process. Modalities of language translation and complexity of work patterns are described in the subthemes.

Language interpretation and preferences of practitioner and patients

Although the provision of language support is a condition for avoiding discriminatory practices in the health service since 2001, the use of interpreters in our data provided many insights of unsatisfactory experiences around this in the clinical encounter. There was evidence that discordant language can be a barrier to understanding even in the presence of interpreters. An experienced primary care participant described her insights.

"So if there's a different language you know you definitely have to make sure that what you've said is being understood. And then there's a lot more checking back as well when they answer, you know check back with them. And with the different culture I think that's much harder." P9 (PC, F, >10, 35-49)

This same participant expressed her doubts about the quality of the interpretation and shared information or doubts based in experiences with professionals that speak the language being used.

"And I want to know what the interpreter has asked them as well. And we have had just a couple of incidents where the doctor who has been involved speaks

something of the language. So, in both cases it was Urdu. But didn't tell the patient they spoke it and they heard the interpreter giving advice which actually was incorrect. So there's always that worry. You never know." P9

In addition, in terms of quality of interpretation, another primary care participant looking after underserved populations had experience with the benefits of continuity of very good interpreters. However, she also expressed her concerns about some interpreters taking the consultation in their own hands. In addition, in her experience, some interpreters were not proficient.

"We've got a lot of regular interpreters that are actually really very, very good that we know well and we work with. Occasionally you can get interpreters that will almost take over the consultation and try and do it for you, especially if they've been medical trained back home. I also have had a couple of instances where the interpreters language skills haven't been that good to the point that the patients have had better English than the interpreter and we have given up with the interpreter. On the whole the ones that we use regularly here are actually really very, very good." P15 (PC, F, >10, 35-49)

Another participant raised the point about interpreters adding their own thoughts to the discussion, which sometimes distorted communication, especially from patient to practitioner.

"And I find if you use professional interpreters, they probably interpret things. And then because they used a lot of medical jargon, they will probably add something to what they say to you which may not be completely what the patient

means. So you get a kind of warped, not necessarily badly, but you don't get what the patient is trying to say." P5 (PC, F, 6-10, 35-49)

The same practitioner also raised a question of discrimination by some interpreters if they are using face-to-face interpretation. This could also distort communication and phone interpretation may be better if this was a problem.

"And in my experience as well, sometimes face-to-face interpreters, they can be very judgemental about the person they are interpreting for. So if it's someone at the end of the phone who cannot see the patient, there are no prejudices almost." P5

The previous participant, a female primary care participant of more than 10 years experience, clarified that it is prerogative of patients and some will prefer phone interpreters to avoid disclosing their identities, especially if there was a traumatic history of sexual trafficking.

"I think it's a preference with patients. Some patients like to have somebody in the room with them or they know a particular interpreter and will specifically say - Can I have that interpreter again… and they will often then see that interpreter when they go to hospital appointments and various other appointments and get to know them very, very well. Some patients especially the trafficked women don't want to be face-to-face cause they don't want to be known what they've gone through and they therefore prefer, some of them prefer telephone interpreters." P15 (PC, F, >10, 35-49)

Not all participants had similar preferences, a female sexual health practitioner with one to five years experience described her preference for face-to-face interpreters, and described that in certain circumstances family interpreters could produce a more supportive interpretation, and benefit the interaction.

"A phone interpreter usually suffice but I find face-to face interpreters often a little bit better. I think that goes for any conversation. Usually face-to-face you get a deeper understanding of what's going on I think. I think you just feel like you can always trust what's being said more because you can see them in the room. It's more personal. So actually for patients being given a diagnosis it might be easier for them because it is that little bit more personal. Although I know the Trust don't like having relatives to translate, sometimes I quite like that, particularly if you feel you can trust them. You know more often than not the relative will want to be caring and want to know exactly what's happening. So actually they are more likely to give a very accurate relay of the discussion you just had. So actually friends or family can be very useful but we usually start with a phone interpreter or a face-to-face one before that." P3 (SC, F, <35, 1-5)

A number of participants, including those of concordant cultural background, expressed their preferences with face-to-face interpreting due to the importance of non-verbal language. This was the experience of a secondary care doctor of non-concordant cultural background who also highlighted not being able to build a rapport due to not being able to maintain eye contact.

"Having face-to-face [interpreters] seems a bit more personal, sometimes I think it's easier in a room to gauge a patients understanding in some ways, it's easy to get a sense of non-verbal communication that you don't see through the telephone. And it's often difficult talking into a phone and you find the patient

talks into the phone, you're talking into the phone and you and the patient are not actually making eye contact, the phone is almost a barrier to the non-verbal communication or being able to build a rapport with the patient in front of you" P10 (SC, M, 1-5, 35-49)

These differential preferences were associated with the confidentiality provided by using a telephone. Establishing good communication and rapport and the value of non-verbal language in face-to-face interpretation were values that could be important to ensure fair communication and informed decision-making.

Complexity of practitioners' work, workload and decision-making

Practitioners described multiple responsibilities and roles distributed during the day, week and year and long working hours. Workload was distributed throughout the day and involved multiple geographical locations and different routines depending on weekday. In an example of response to the question, "can you describe your roles and responsibilities within your job?" a GP described having to fit in patient review, training of registrars, administrative responsibilities and nursing home visits.

"I am a GP partner in a rural practice and educator for the GP training scheme… We see fifteen patients in the morning and twenty patients in the afternoon; and on average two to three home visits. A day on-call every week, which is mostly telephone triage and we will bring a few patients down from that. We have the care home so every other Wednesday I will go and do a ward round on the intermediate care. The care home in itself with all the residents keep us extremely busy; partly because we don't have the time to actually sort things out properly

at this time. There isn't really much time. Most of my paperwork resorts reading through letters that I tend to do in the evening when I come home. Just because there isn't enough time to do it normally in the daytime. P4 (PC, M, 1-5, 35-49)

There were other similar descriptions given with some variations but in general describe multiple responsibilities and long hours of work. Both in primary and secondary care responsibilities were distributed between clinical assessments in the place of work or in other places such as nursing homes, peripheral units, different hospitals or surgeries. Additional educational, administrative and research roles were described, as well as being part of non-NHS organizations or dealing with commissioning, policy, education or research.

Some parts of clinical care happened outside the clinical encounter; for example, the reviewing of test results outside consultation time. Practitioners may make decisions that do not involve the patient in following protocols triggered by abnormalities in the tests results. A participant describes the process of decision-making to test and reflects on the outcome of tests and communication with patients.

"For those people where I am just doing it as part of a non-invasive liver screen because their liver tests, I don't intend to tell them. I just say I am going to do a few more blood tests for some rarer conditions. Come back and see me for the results. So if it came back [positive] it probably would be a difficult conversation to have perhaps." P4 (PC, M, 1-5, 35-49)

Another participant also reflects in the same process of deciding away from the clinical encounter and communicating requested tests to patients. The participant describes the practice of responding to abnormal liver tests. While discussing whether patients were aware of which tests they were being offered, the motivation for communicating those was not related to the implications of a diagnosis being made.

"Because usually what happens is that you'll get the abnormal liver function test and you might not know why it's abnormal. At the moment that you start to get abnormal liver function tests that you don't understand why, then hepatitis screen may be part of that but you are making that decision without the patient in front of you. Ok, right so the patient's gone now and you bring them back just for a blood test. I always say to patients because they are going to have the blood test done in surgery, in which case it's on the computer and they can see it. Or they are going to take a piece of paper away and go to have the blood test at the hospital." P9 (PC, F, >10, 35-49)

These were examples where discussion and decision to test did not happen in the clinical encounter. The decision to do some more tests may have been communicated but the implications of a diagnosis had not been discussed. From another point of view, although testing were done in these circumstances it was clear that these examples will not necessarily reach those at risk. In addition, these exclude a majority of people with chronic hepatitis B that have normal liver tests, and people at risk at an age not yet requiring cardiovascular assessment.

4.4. Organizational factors affecting decision-making

Participants identified directly or indirectly organizational issues that could prevent a proactive practice to help those affected accessing health care services. The difficulties of undertaking work within an already stretched workload and the lack of clarity for funding responsibilities are highlighted by practitioners from different areas of the health service. There was a lack of patient information support and infrastructure support. In addition, innovative services were difficult to develop in the current climate and although some examples remained, others had not been sustained. These gaps embedded in the system could be seen as a representation of structural racism; they are factors that hinder equitable access to health care for minority populations.

4.4.1. Theme: Professional and organizational support

Professional support involved assistance provided by the organization where the health practitioner worked or by the NHS in general. Wider support systems included nationally overseeing institutions such as NICE and professional colleges. Examples of support for practitioners around chronic hepatitis B management included ad-hoc local contacts in specialised departments or public health bodies. In addition, patient information support around the condition helped support the work of the practitioner by providing a written information reference, but this was not always available.

Support for practitioners

When practitioners required support or information about management of chronic hepatitis B, the narratives described different avenues that depended of the practitioner contact with other services, or system prompts.

Describing how difficult the interpretation of results for chronic hepatitis B could be for practitioners, a primary care participant explains that interpreting chronic hepatitis B results was not a task performed regularly. Therefore, it needed to be supported by reading, although this gap was not expected to affect management.

"I reckon if you were to put down some Hepatitis B results in front of any of us, like the GP trainees or the trainers, I suspect we would probably have to go and have a little read on the internet or in the books. I think we would all know what to do and what action to take but I guess there is only one or two of us we that might be able to interpret." P4 (PC, M, 1-5, 35-49)

When asked whether there was professional support available for practitioners another primary care participant described the options available to her. Similar options were also described by other primary care and community based participants.

"I have phoned up either ID registrars if I need any more help or advice about things, but also the Health Protection Agency because I know there is always someone at the end of the line." P5 (PC, F, 6-10, 35-49)

Another practitioner had a similar option of support by contacting infectious diseases specialists and described the prompts embedded in the system with automatic recall or reminders for scheduled immunizations for example.

"If we have any doubts we phone the hospital, if we had queries we just talk to someone, and with the vaccinations we have the recall systems, we follow them all up which I think is pretty good, its what we do here" P1 (PC, F, 6-10, 50-64)

Professional support was needed when addressing chronic hepatitis B but was not consistent. It could take many different forms such as reminders, availability of specialists at the end of the phone or availability of scientific information.

Another area of support for practitioners included information of how to best work with interpreters. This was mentioned in the context of post-graduate training. Training in the use of interpreters was provided to doctors entering primary care in the last few years, but not to secondary care doctors and all those that entered the profession before the training was implemented.

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"How to use interpreters it's been regularly part of Sheffield's training scheme for General Practice. This is training that is open to those whilst they're training, probably since… certainly 5 years possibly 7 or 8 years quite a reasonable amount of time. …There have been courses run by RCGP [Royal College of General Practitioners] for working with interpreters, I think that has been run independently but it's not a regularly done thing." P12 (PC, M, >10, 50-64)

The answers to the question of whether other participants received training in the use of interpreters were mostly negative and in some cases had not even been considered as a need.

Supporting information for patients

This subtheme shows some examples of the type of information support practitioners have mentioned in their narratives. There were different ways of accessing it and different attitudes towards printed information. Some wished they had available information that concisely explained chronic hepatitis B.

A primary care participant mentioned written information about chronic hepatitis B in their interview as desirable resources to support their work and other participants were asked about it in interviews in order to clarify what is available.

"We tend to use a lot of patient information leaflets, anything on patient.co.uk for example, for patients who can understand English. And generally, if there are lots of questions, I tend to print something out for them and ask them to ring or make another appointment." P5 (PC, F, 6-10, 35-49)

In the case of hepatitis B testing being part of required testing during pregnancy, a midwife considered the information sufficient since many other issues needed to be discussed in the booking appointment and would not be a priority.

"I think the screening leaflet that we give out does cover it really well of what we screen for. So that's obviously giving the verbal information and then backing that up with literature. It's an hour's booking but you have got a lot of information to give. And you are giving so much information at booking, it's difficult; I don't think you will ever know which bits they are homing on, which bits they remember, which bits they don't, because there's so much information. It's information overload…" (Co, F, 1-5, 34-49)

Another participant from primary care also believed that written information is useful but the information about chronic hepatitis B can be too much for patients, and describes a stepwise approach.

"I give them the leaflet in English but I think it carries so much information, I would have difficulty absorbing it all quite honestly. It has to be taken in steps; and then I refer down to the local hospital where they have a nurse practitioner who is superb at giving them all the information, I don't feel that just stops with me, I figure I'm just the starting point." P11 (PC, F, >10, 50-64)

When asked about barriers or how to facilitate the process, a participant was reflecting on information available for patients. She mentions that even written information may not be useful for all patients.

"Probably one of the things we could do is to look at some more written documentation… Just basic things, like this is what hepatitis is… just an

information leaflet and reinforcing the importance of going for the hospital appointments and why is important to go for them, but I am not too sure, I am not sure how literate a lot of them are…" P1 (PC, F, 6-10, 50-64)

The availability of printed information was seen as desirable. However, in cases where this was available, it was considered complex, probably reflecting the complexity of the disease, combined with the difficulty in explaining an asymptomatic condition and the uncertainties and variability of chronic hepatitis B prognosis.

Language interpretation infrastructure

The purpose of interpreting was to make possible the two-way communication or any other process required during the clinical encounter that needed explaining. In addition to the difficulties intrinsic to interpretation described in the previous section (4.3.1), technicalities also hindered the process. All practitioners had access to interpreters. However, in two instances participants described having a clinical encounter without an interpreter. Here the English level was not sufficient for the required discussion therefore had to be followed-up with a consultation where an interpreter was available.

Many practitioners mentioned using telephone interpretation, but the availability of infrastructure varied from hands-free equipment to normal phones without a speaker that required passing the handset from practitioner to patient. A participant looking after underserved populations described the dated equipment available in the service that impeded fluid consultation and examination.

"We don't have headset or anything like that… not very good with technology and fairly elderly our system. We struggle with the telephone; how can you possibly examine somebody if you have a phone under your elbow at the time. Try doing a [cervical] smear with a telephone tucked into your arm" P11 (PC, F, >10, 50-64)

Another primary care practitioner also described the process of using inappropriate systems for interpretation when the consultation involves more than talking.

"New acute illnesses are harder to manage and telephone interpretation is available but that's not without its delays and problems… Slow, clunky, examination how do you bring the phone when you are explaining what to do… lay on that, sit you have to work out. So can you tell him that I'm going to ask him to do this, then I am going to ask him to do that … lung examination, rectal examination will be doing this all before you are there, because you are then three yards from the phone so you can't explain what you are doing" P12 (PC, M, >10, 50-64)

The infrastructure described by a dentistry school participant is at the other end of the spectrum, reflecting very different access to infrastructure in distinct settings. The participant also appreciates the advantages of having a phone service that can be available at short notice.

"We've got a phone system so we phone mmm…, I don't know who the interpreting service is; we can phone and then ask for an interpreter; it's usually the dentist with a headset if you want a headset and then the patient has the

other [headset]. It saves having to book an interpreter, which was a real pain. You know and if someone turned up as a casual patient you know you are getting somebody." P13 (SC, F, >10, 50-64)

Appropriate interpreting infrastructure is not always available to practitioners adding a further layer of complexity to the already difficult task of ensuring efficient communication through linguistic and cultural differences.

Innovation and sustainability

Innovation and successful service development were mostly established in the previous decade. For example developing a service for asylum seekers and refugees, and hiring a culturally congruent support worker, were achieved around the turn of century. A practitioner described how the development of a service for asylum seekers and refugees developed in the late 1990s.

"In 1999 when the new national asylum support service was set up by the Government and started to disperse asylum seekers… it was almost like dealing cards out, people got sent to various practices around the town. I thought it would be really good to set up a separate service for asylum seekers and the PCT [Primary Care Trust] were very receptive to this; they were willing to support our proposal and so it was relatively straight forward." P11 (PC, F, >10, 50-64)

The same practitioner reports more recent problems with services of this type around the country; these followed changes in policy and the Health and Social Care Act of 2012.

"Things have changed dramatically across the country. There was a practice in [large regional city] which, was open for years and the PCT just said we can't

support it anymore and so now they don't have a separate service. The service in [small regional city] was also stopped… there's a lot of resistance there, and I know that other practices round the country are working on a salaried service; and other practices have merged services with mainstream practices." P11

Other innovative practices exemplify how services have looked for facilitators to provide equal care to minority populations. The example is from a primary care service with a large Chinese population. A support worker has worked here for many years and has adopted a strategy to facilitate the clinical encounter as described by this participant.

"…since when I joined it which is 14 years ago or so, the practice has employed a Chinese worker as an interpreter who has a background as a social worker I believe, who spoke fluent Cantonese and had more than passable Mandarin, she was competent and indeed much better than most commercially available interpreters. She worked with an understanding of a patient centred approach. Her integration into the team meant that she was effective at taking a history from the patient. In the waiting room she would find out what their concerns were, and when the consultation started she worked as an interpreter but she had the context, so where you might get uncertainty she had already done the work." P12 (PC, M, >10, 50-65)

The same participant described how the Chinese worker also helped people fluent in English if she was available. However, urgent appointments with patients less fluent in English, where the worker had not been previously booked, were less than satisfactory.

"We had people who had, even if little fluent in English, will refer to in English and will not ask for an interpreter. Unless they were Chinese in which case yes they may be fluent they might still ask for X [worker's name] to come. But we had people who if X wasn't available, could cope; it wasn't as good … and they would ask me – please phone X next week, she can look at my notes and she'll make sure you have understood what I have said – or something like that." P12

These innovations aimed to facilitate access to health services and effective communication and understanding, targeting individual's needs and facilitating service delivery. These examples had been set up 12 to 15 years previously and the health system structure had changed since. The opinion of the same participant was that it would not be practical to develop this for all the underserved communities by relying on individual practices, but a more centralised system or a community-based system could be more efficient.

"Yes, the system makes it hard, what would improve it? There is no doubt that better interpreters would improve it. it's likely that the model of community centres, like the Chinese community centre, facilitating people being interpreters and working with primary care, is a more replicable model than practices employing an interpreter, its more transportable, its more flexible, it's more likely to be funded because people doing it will have multi potentiality rather than being fixed and in one place. The question is how can you have more. We need a Slovak support centre which is able to work with that community we need… there is a Yemeni support group but I don't think they have an interpreters and they don't have any support or any funding that I am aware of." P12

A more recent innovation was that of a Local Enhanced Service for hepatitis B, aiming to offer testing in a population with low access to health care and high mobility. This was originally proposed by primary care clinicians working in an area of high density of this group that had taken the initiative to offer testing to all new patients attending the service between 2007 and 2012 and found a 9.4% prevalence of active infection (Gregory et al., 2014). I have described this innovation in the next theme as it also relates to commissioning.

4.4.2. Theme: Commissioning and competing priorities

This theme looks at the issues that can indirectly influence clinical decision-making in the clinical encounter by means of national policy or funding of services. Much of the description of practitioners' work included increasing or changing workload or new ways of working generated by structural changes in the organization of the NHS.

Commissioning priorities and resource allocation

The practitioner that expressed good clinical practice as a motivation for testing (section 4.2.1) explained how this may be hindered by the lack of opportunity in terms of workload and resources in case of large number of patients requiring testing. He described a comparable example from another local primary care service and from a public health measure requested from primary care.

"Having talked to colleagues who work at [GP surgery] where they have a huge population of Slovak Roma [patients], I could understand why those practices would want to have it more formalised; to have that time paid for, because it would be a lot of work. I think it is something like adding a rotavirus to every child, which is lots of patients; we'd probably expect there to be some money attached to it to do it." P4 (PC, M, 1-5, 35-49)

Other illustrations in clinicians' narratives addressed uncertainties about responsibilities with testing and how could testing be implemented without much disruption. This practitioner also raised the question that uncertainty about funding could influence clinical decisions.

"You've got to make a case; if it can be delivered in a way that's as painless as possible, with good evidence and you know... cost neutral… But if I screened all our high-risk groups and found we had ten hidden in all the clinics, then what happens if we then refer them on? Will the department have to pay for the treatment or is it going to be taken on by primary care, or ID (infectious diseases)*? So, that would make a difference I suspect"* P14 (SC, M, >10, 50-64)

The following quotes are from a participant who had an advisory commissioning role. She first described the difficulties in setting up an enhanced local service for testing of hepatitis B in a newly identified high prevalence community, which did not fit with commissioning priorities.

"It was presented to the governing body with the written evidence (of high prevalence) and the proposal. And there was lots of humming and aaahing … as it is not part of the commissioning intentions; there is no budget for it. But, you know it isn't a huge amount of money in the grand scheme of things and it is preventative as well." P9 (PC, F, >10, 35-49)

The participant also described how the commissioning body thought of such service as a responsibility for public health bodies rather than primary care services. This showed that it was unclear where responsibilities for such services laid, and that had not been clarified nationally, creating frustration in practitioners.

"The CCG management were very much of the opinion that actually this immunization and screening isn't CCG [Clinical Commissioning Group] business. They thought it was more public health because it sits under the immunization

[responsibilities] and that's public health. But you could have waited for NHS England, Public Health England to move mountains, it will never happen." P9

The same participant explained how a moral duty of providing care was what tipped the balance and how funding was provided. She indicated that it was thought that the service was needed but the conflict was around funding, despite the contradictory statement that provision of such service fitted with national priorities.

"It took one person to say I'm sorry that's not good enough. Somebody has to pay this and we can't allow… It was the idea of children having Hepatitis B and us not knowing about it. Not being treated and not being managed. And it would increase morbidity and mortality. This is an unmet need in an underserved population and we know that it's not an outlier; it's right up there with the leaders in liver associated deaths." P9

In addition, the same participant described a lack of structured information in defining priorities by commissioning bodies, making priorities dependent on commissioners or advisers experience.

"Sometimes priorities are decided on without people knowing what the difficulties are. So for example, the [high HBV prevalence group] community is a case in point. There are five practices out of more than eighty in [locality] that are aware of the issues. So if I weren't sitting on the governing body, then somebody else from a practice that wasn't involved with the [high HBV prevalence group], would it have been given the same prominence? I don't know." P9

The examples showed lack of clarity of the pathways for prioritizing clinical needs in circumscribed populations. This represented a marginalization of the agenda for providing equitable health care (Salway et al., 2016). It revealed that uncertainties that exist in regards to funding at different levels of service were affecting good clinical practice even when the best knowledge and motivations were considered. The unclear paths for funding created a setting of conflicting priorities.

Narratives also demonstrated areas where conflict of interest occurred in practice. Areas described include reduced funding in primary care with increasing workload, conflict about funding of needed service developments, and conflict between maintaining continuity of care and work balance or satisfaction. A description by a clinician caring for a large population of Chinese ethnicity gave a perspective of challenging times around increasing work, with reduced funding for primary care, and a conflicting comparison with secondary care.

"Its difficult, it requires investment; the sad reality is that the proportion of the NHS cake that has been spent within primary care, has shrunk every year over the last 10 years while the proportion that has been spent within secondary care has increased, whereas the workload has gone in the opposite direction. [For example] 15 years ago 70% of diabetics in [city] were managed with hospital input, I think the proportion is now down to 10-15% I guess, [I am] being generous to secondary care. That work hasn't gone away and there are more diabetics than there were [15 years ago]." P12 (PC, M, >10, 50-64)

In addressing the current crisis of overwork and low funding in primary care, the same participant described how independent practices have to manage their funding and how this conflicts in addressing needs of patients.

"So we have an incredible problem with under funding of primary care, over working of primary care, under recruitment to primary care posts. An independent practice status for primary care, which means a decision has to be made about whether you take home as much money as other people do or whether you fund somebody to be an interpreter in your practice. There is a commercial challenge there." P12

Another primary care practitioner described how policy decisions around pensions and increasingly unsatisfactory workload conflicts with providing best patient care and continuity, prompting GPs to move or retire.

"Those GP's old enough to retire are retiring because they're getting fed up of it, and with the changes government have made to the pension and the difficulties with the job, they chose to retire and work a few sessions as locums. Everybody else is trying to make general practice work in the hope that at some point it's going to get easier, and we care about patients, we care about the staff but it is getting harder and harder and I think more people will leave or move around. I think there's a lot more fluidity with doctors moving round within surgeries and between surgeries." P15 (PC, F, >10, 35-49)

These views reflected conflict arising from working conditions, conflict between service areas and dissatisfaction with workload and responsibilities that can negatively influence practice and continuity of care. The narratives showed these decisions were not easy to make and were due to dissatisfaction with persistently difficult to manage workload.

When I asked a participant about professionals that question offering testing based in the premise of limited funding and resources, her response described the contradiction in values and defined the main aim of health services as preventing morbidity.

"It's like the TB questions. If we screen them, what will we do? You know it is a completely ridiculous argument. It is like 'burying your head in the sand and pretending they are not there'. There was the original business case for TB screening. I do not think they were looking at screening everybody but what you would save. I do not think you just look at the financial cost, do you? You look at morbidity and you look at the individual cost to the family, the cost to the community. That's our business isn't it?" P9 (PC, F, >10, 35-49)

This last quote defined clearly not only conflicts of motivation and interest, but also how the economic discourse affected the prioritization of health professionals' values.

There were also difficulties with financing services; this was reported from communications between professionals during appraisals.

"Only thing I can say as my role as appraiser of other GPs is what I hear second hand of fitting new premises, new services to be approved; now it's much more difficult with constraints financially." P11 (PC, F, >10, 50-64)

The experiences around commissioning in this study demonstrated lack of clarity of values and priorities, the agenda of equity in health care was superseded by the economic agenda. The reports of GPs describe a scenario of funding shortening that resulted in lack of innovative service developments, unmanageable workload in primary care, and lack of continuity of care for patients due to high mobility and prompt retirement of GPs. The following section depicts in more detail the increasing workload of primary care.

Organizational changes and conflicting responsibilities

Organizational problems arose from a reorganization of the NHS that started in 2012 with the Health and Social Care Act, including fragmentation and uncertainty about responsibilities and funding (Gadsby et al., 2017). A reflection of these emerged in various narratives but in particular in one interview, which I describe next.

A clinician explained that unclear boundaries and increasing responsibilities could cause problems in managing workload. He acknowledged many functions of primary care that may change in volume and tip the balance, affecting practitioners' motivation.

"Primary care, would see itself normally as being demand led so it responds to what comes through the door, I think there is a myth there, I think primary care mainly has three functions … and it struggles to do all of them, they are interlinked but it is complicated doing all of them and valuing each of them." P12 (PC, M, >10, 50-64)

The description of three functions of primary care was based in his experience as a General Practitioner and GP educator. His insights revealed that primary care was receiving more demands from secondary care, public health and patients.

"So there is an acute provision that used to be a large amount of primary care, if you go back 50 years, in many ways because anyone with a complex problem would be looked after by a hospital. Hospitals have stopped doing that, so the second bit is managing pretty much any chronic illness that affects patients. And the third element of primary care is provision of public health. It is the most practical; because we have a list-based system we have the most effective system from the public health perspective." P12

Furthermore, he explained what he calls the public health role of primary care and assessed it as increasingly impractical when the objectives are not fully informed by evidence and improved outcomes.

"So that works quite well for immunizations, it works ok for cervical screening, things that GPs are paid for either to do or for hitting a percentage of people who had it. It works less well when GPs are asked to do things they think are daft… not mentioning a 10% suggestion on cardiovascular risk in relation to lipids which I think there is a disjunction between what is theoretically possible, what is really possible to persuade most people of, and what most GPs practice." P12

The same participant described that there were conflicts with duties moved from secondary care to primary care, and again a lack of defined responsibility for the work shared between primary and secondary care.

"Many of my colleagues would be concerned about heart failure nurses who will do some things, do tests, and then say it's the GPs' responsibility [to follow-up]*, so I came in, I did this, but it's your responsibility to deal with the blood test I take."* P12

Although the examples did not relate directly to chronic hepatitis B or migrants groups, these pointed out to increasing demand on primary care services, conflicts between primary and secondary care and dissatisfaction of practitioners with the workload.

Next section concludes the chapter.

4.5. Chapter conclusion

The interpretive findings point to barriers and mechanisms acting at different levels of service provision that influence how adjudication and offer in the candidacy model (Dixon-Woods et al., 2006) are accomplished.

Individual and organizational factors interact to facilitate or hinder the interaction during the clinical encounter. Barriers at personal or professional level such as lack of knowledge of risk for CHB were counter balanced with principles of good medical practice or by professional support such as contacting other agencies. However, organizational factors directly hindered the clinical pathway with structural deficits such as lack of interpretation infrastructure. Other fundamental organizational issues included conflicts of interest, increasing workload and uncertainty around responsibilities and funding, which compounds a lack of acknowledgment of the health care needs of minority groups.

The overall key findings from this study, their relation to published literature and their relevance to policy, practice and research are discussed in the next chapter.

5. Discussion

This chapter summarizes the key findings of the study and discuses how these contribute to current knowledge. This study aimed to elicit modifiable barriers and facilitators by exploring practitioners' experiences and views. The results are discussed in the context of current knowledge and how could the findings contribute to practice, policy and future research. Study strengths, limitations and generalizability of key findings in the context of the philosophical position of the research and the study aims and context are discussed. In line with its aims and objectives, this study explored practitioners' roles, responsibilities and experiences using semi-structured interviews to understand factors affecting access to health care for chronic hepatitis B in Chinese populations.

This is the first in-depth study to address the role of practitioners and services in facilitating or hindering access to health care focusing on chronic hepatitis B in the particular case of populations of Chinese ethnicity resident in the UK.

5.1. Summary of key findings

Key findings derived from the interpretive analysis are presented here using the main categories of themes. Key factors act at different levels of the practitioners' role in health care access. The balance between factors at different levels sometimes was conflictive and not conducive to facilitating access as explained next.

Individual professional factors that have a direct influence in clinical practice included professional capabilities and principles that guide practice. Although these were present in the narratives, and had the potential to improve access, in many examples these were not sufficient to oppose structural or organizational barriers or to resolve communication issues.

Factors that were evident during the clinical encounter related to the ability to attain a fair interaction with patients. Communication skills seemed insufficient to achieve decision-making that was in line with patient's choice. These included barriers in verbal and non-verbal communication across languages and culture, and external factors influencing the encounter such as difficulties with the complexity of work patterns and excessive workload.

Wider organizational factors were ineffective in providing a supportive context where shared decisions could be achieved. In addition, there was a lack of local and national support systems within health care organizations to address the problem of undiagnosed chronic hepatitis B. Health needs of minority groups including those of Chinese ethnicity were marginalized and responsibilities were unclear.

5.1.1. Professional and personal values guide practice but there are gaps in awareness and knowledge

In the process of providing care for chronic hepatitis B to populations that are at higher risk than the majority population in the UK, practitioners used professional principles of clinical practice, personal values, and clinical skills and knowledge about the condition, and about the population.

Some of the findings indicated enabling factors. The participants' narrative indicated the use of rational thinking directed to achieving effective practice; this included identifying priorities in patients' health needs and facilitating patients' engagement with services. This was particularly important in populations that encounter structural barriers in accessing health care services and in making their needs known, which included migrant populations. Practitioners' valuing of inclusion was evident in many narratives reflecting awareness of the difficulties some patients may encounter and the practitioners' efforts to try understand and bypass those barriers. This was mentioned for example as the main aim of innovative practices such as those caring for asylum seekers and refugees, or those caring for large groups of migrants from Hong Kong or China. These innovations were few and developed more than ten or fifteen years ago but had been effective in addressing the identified barriers that prompted them.

An aspect of individual factors where barriers exist was knowledge and skills in relation to chronic hepatitis B. The use of rational thinking around abnormalities of the liver prompted testing for viral hepatitis among other tests. However, in many narratives, practitioners recognised gaps in knowledge, and management, and in previous and current medical training. It was clear that there was lack of familiarity with the concepts of high prevalence and family history indicating vertical transmission. Only those practitioners looking after patients with hepatitis B understood the diagnostic complexity it entails. Guidelines aimed to improve diagnosis of people at risk were generally unknown except to hepatitis specialists.

5.1.2. Clinical encounter communication barriers and shared decision making

Communication difficulties contributed to inefficient or inappropriate health care and service provision for chronic hepatitis B. The complexity involved in discussing medical concepts in general and of chronic hepatitis B in particular was a theme that added to what is already known in medical communication barriers. Effective communication was essential to assess health issues accurately and to provide appropriate and safe care. In this study, barriers of communication were identified in spoken communication across cultures. Non-verbal nuanced expressions that were highlighted by practitioners of shared cultural background, contributed to miscommunication and misunderstanding of patients health needs and preferences. There was evidence that efficient cross-cultural care was not consistent.

5.1.3. Organizational support is insufficient for diagnosing chronic hepatitis B

Support systems for practitioners dealing with diagnosing a complex condition in a minority population that speaks a different language were insufficient. Narratives showed difficulties with facilities for effective interpretation, lack of supporting information for hepatitis B and lack of promotion and awareness of guidelines. In addition, lack of clarity around responsibilities and funding, in a context of health service structural change, added to these barriers.

The low priority for chronic hepatitis B nationally and low awareness of guidelines occurred in a service context that was challenging for practitioners. Identified barriers included increased workload, uncertainty about where responsibilities for care lay, and budgetary constraints. Although these factors do not fully explain the disparities in access to health care services, they appeared as contributing to the lack of priority given to asymptomatic conditions that are not well understood such as chronic hepatitis B.

Increasing workload meant that practitioners had priority strategies to cope with it. Participants who were clinicians described complex roles, long hours of work, the need to prioritize urgent actions in detriment of less urgent ones.

Other system related problems included increased mobility of practitioners making it difficult to have continuity of care and address less pressing conditions. These factors, compounded with conflicts of interest and lack of support for addressing local needs resulted in a general low morale about implementing necessary change in their practice.

The factors identified in this study may have commonalities in other conditions and populations. Some were related particularly to chronic hepatitis B and some could be attributed to failure to adequately communicate with populations of different language and culture. Institutional barriers of lack of awareness and support for relevant health needs of discrete groups of the population were reflected throughout the data. This study offers insight on service and practitioner factors and how these can work as barriers and I discuss this in the next section.

5.2. Findings in relation to previous research

Access to health care services for chronic hepatitis B in England and worldwide has been shown to be insufficient in diagnosing and treating before complications occur (Locarnini et al., 2015; Evlampidou et al., 2016; Falla et al., 2017). The wider study literature review of associated factors showed that studies mostly addressed population barriers; and that these have been studied mostly in USA although some studies are based in Canada, Europe and Australia (Vedio et al., 2017). This study contributes to understanding barriers related to practitioners working within the National Health Service in England.

The process of making access to health care services possible for patients with chronic hepatitis B and of Chinese ethnicity showed layers of complexity. The most salient barriers found in this study can be summarised into three major areas. These are communication barriers, cross-cultural barriers and organizational barriers. Communication barriers are related to two areas, information about chronic hepatitis B in order to facilitate diagnosis or treatment, and discordant language communication. Cross-cultural care factors are presented in relation to the concept of cultural humility to understand how the barriers can be approached. These also relate to non-verbal language and assumptions by practitioners. Finally, the organizational barriers include widely spread gaps in support for practitioners and patients, uncertainty about responsibilities and conflicting clinical and financial priorities; these reflected the persistence of institutional and structural racism.

Note to the reader: reference to this study of practitioners will always be called “this study”. When other published studies are discussed, the author’s name will be used.

5.2.1. Discussing information about chronic hepatitis B

Charles et al. (1999) described the initial step in shared decision-making as exchange of information. This provides the physician and the patient with the basis for deliberation to make treatment decisions relevant to both. Discussing the rationale of offering tests for hepatitis B was a difficulty reported in primary care and in midwifery services. Participants' narratives directly acknowledged the difficulty of transmitting information about the condition and difficulties in understanding the impact this could have for the individual. Communicating information is of particular importance to prevent mother to child transmission at birth and in the first year of life (World Health Organization, 2013). The literature review, in a survey study published by Chao et al. (2012) showed that midwives did not communicate important information despite being aware of its importance. When the study was followed up with a qualitative study (Yang et al., 2013) midwives and obstetricians found their confidence was low in explaining hepatitis B and they were afraid of communicating wrong information.

The large amount of information given in leaflets about chronic hepatitis B was thought to be impractical to discuss and relied on future explanations given in specialist clinics. When interviewing participants familiar with treating chronic hepatitis B, these also highlighted the complexity of communicating the information about the condition. These clinicians were particularly concerned about chronic hepatitis B being difficult to explain in a manner that can help understanding and that is relevant to patients. This was especially important when decisions about treatment needed to be made. Consistent with this, a qualitative study in Australia, assessing information provided by specialists about chronic hepatitis B, identified a lack of consistency in information provided across cultural and language differences (Wallace et al., 2017). Particular emphasis was given to the explanation of the phases of the disease which could make sense to an Australian fluent in English, but that can be extremely difficult to translate into a different language. The study by Wallace also determined what issues practitioners though to be important to communicate. This included the importance of preventive advice, the need to understand if stigma is a barrier and the need to iterate the advice in subsequent consultations with the same individual due to the complexity of chronic hepatitis B. Their findings are concordant with the findings of this study and with previous literature explored in Chapter 2. These findings demonstrate that this is a general issue with chronic hepatitis B information, adding a further layer to existing practitioner related barriers to adequate diagnosis and treatment.

Not surprisingly, this study detected gaps in the medical knowledge that guided practice, and participants' lack of understanding about the condition. Old superseded theories about chronic hepatitis B, lack of awareness of the long-term effects of the condition, gaps in awareness of vertical transmission, meant that preventive measures could be difficult to institute. These results could be thought to reflect the ages of those who provided data revealing out-dated information from training before the late 1990's. However, when training issues were explored, inconsistencies and poor knowledge of the condition even in participants who trained more recently and those that train junior colleagues emerged. Younger doctors and trainers of GPs identified hepatitis B as part of a list of differential diagnosis but did not recall specific teaching about it. This finding may explain the low confidence of practitioners about their knowledge and capacity to manage chronic hepatitis B (Sweeney et al., 2015), in providing preventive advice (Yang et al., 2013), and the evidence of insufficient preparation during medical school and post-graduate training (Chao et al., 2015). Chronic hepatitis B seems to fall between the gaps of low priority in England (Evlampidou et al., 2016) and complex challenges in medical education (Sandars et al., 2015); and this may explain its absence in medical training. There is a need for specialist clinical management of chronic hepatitis B and access to correct support resources for generalists and patients (Wallace et al., 2017).

5.2.2. Language barriers, interpreters and clinical safety

This study shows that communication is a factor affected by multiple issues.

Discordant language was reported to be a challenge that was not easily resolved and participants described frustration even with professional interpreters. The importance of providing professional interpreters for health care encounters has been widely studied, demonstrating that outcomes significantly improve when these are available (Flores, 2005; Karliner et al., 2007); and that major difficulties were found with the use of informal interpreters (MacFarlane et al., 2009). One participant in this study thought that informal interpreters could provide the extra support needed when a serious diagnosis was received, but other participants had mentioned informal interpreters as limiting the communication of confidential issues and hampering communication with their own caring agenda. Flores et al. (2007), in a systematic review conclude that the use of professional interpreters improves quality of care and reduces the use of superfluous resources. However, in a systematic meta-ethnographic review of qualitative literature, understanding the complexity of language and the importance of building continuity, trust and professionalism of interpreters were considered essential factors for these essential roles to be effective (Brisset et al., 2013).

This study showed that the lack of interpreter or the translation being insufficient or erroneous could limit the understanding by the practitioners of the impact of the condition on the patient’s life. In addition, it highlighted difficulties in properly assessing needs without adequate interpretation, and confirmed frustration both for the health care practitioner and for the patient. This phenomenon was also reported by key informants and in the community arm of the wider study. Consistent with these findings, a previous mixed methods study in Norway showed physicians perceived many barriers to communication even with professional interpreters. Among these were not being able to identify accuracy of interpretation and not being able to understand the health, social and emotional contexts of the individual (Hanssen et al., 2010). Similarly, an observational study of district nurses home visits showed that nurses carried out procedures without being able to assess other aspects of patient concerns, whilst patients that were fluent in English discussed many concerns directly associated with the treatment received, highlighting the disparity in access and the increased clinical risk (Gerrish, 2001).

In Canada, a knowledge translation study showed that discordant language presented risks for serious clinical errors even when using interpreters (Bowen et al., 2010). In this study, there were concerns with errors of translation and these were not easy to detect. Language barriers should be considered safety and quality issues based on the high proportion and the seriousness of clinical errors triggered by errors in language interpretation (Bowen, 2015). The report by Bowen (2015) describes the tendency to see language as "*a soft issue*", and recommends considering language barriers a safety issue involved in preventing clinical errors. This study supports the view that the quality of interpretation can have a major role in preventing clinical errors and in understanding patients' context.

Discordant language as a barrier in communicating health issues was perceived by general practitioners to be the main issue involved in barriers to access to health care for chronic viral hepatitis in Europe (Falla et al., 2017). In this study, participants who used interpreters with most of their patients showed an understanding of the difficulties arising from trying to communicate in different languages especially in making sense of medical explanations and in clarifying messages. Similarly, the European survey showed clinicians in the UK, the Netherlands and Germany were more aware that language posed a barrier to accessing care for viral hepatitis than clinicians in other countries in Europe, especially those living in countries that do not provide interpreters for health care encounters (Falla et al., 2017). In this study, many participants working in secondary care and some in primary care reported that they never received training on how to use interpreters or how to efficiently check for misunderstandings during translation. Training in the use of interpreters has been identified as one important factor that can decrease inequalities in health care provision (Diamond et al., 2010). Using interpreters is a complex intervention that requires particular skills and that these skills can be learnt (Bansal et al., 2014), but this study showed that training had not been implemented widely in the NHS.

The issues discussed in this section can be seen as arising from structural and historical barriers of marginalization of the needs of language discordant groups (Salway et al., 2016). These factors represent barriers that combined with the practitioners' uncertainty and lack of clarity about funding and responsibilities, hinder access to health care services for these groups.

5.2.3. Cross-cultural communication and care

Communication across cultures and associated barriers has been studied considerably in health care. As discussed above, studies have focused on working with, and training to use interpreters (Gerrish et al., 2004; Kai, 2005; Diamond et al., 2010; Bansal et al., 2014), understanding the effects of language errors (Bowen et al., 2010) and of the effects of uncertainty on health care delivery y practitioners (Kai et al., 2007) among other issues. In this study, a participant of concordant ethnicity described clearly, how Chinese patients felt frustration at the misinterpretation and misdiagnosis of their concerns. One example provided revealed that a patient was prescribed treatment for depression after their recurrent visits were not interpreted as lack of resolution of the patient's concern, but as a mental health issue. The clinician with related cultural background who understood there were concerns and explored further, identified the patient's problem and the error in clinical diagnosis. He thought that using consultation skills such as reflect questioning or understanding hidden agendas, would be sufficient to identify the concerns of patients of Chinese ethnicity. Individuals' preferences are considerably misdiagnosed contributing to miscommunication in health care encounters (Mulley et al., 2012). In the report by Mulley, preference misdiagnosis was associated to clinician assumptions about the underlying reasons patients may have in the process of seeking health care, and was a contributing factor in clinical errors.

The data about complexity of communication showed difficulties in discussing information about chronic hepatitis B, difficulties in understanding patient priorities and choice, and misunderstanding of cultural patterns and preferences.

The narratives from participants of shared cultural background helped to dissect further those of other participants and deepen the understanding of barriers. The mainstream cultural habits in communication were identified by participants of Chinese ethnicity, that used it either to explain differences or similarities with their shared cultural background. Importantly, these views were also shared by some participants of non-shared cultural background with extensive experience working with migrant populations. However, many practitioners inferred that patients of Chinese ethnicity presented without many problems and seemed engaged in their health care, or interpreted them as reserved. These assumptions correlated more with the practitioners' own cultural attitudes than with differences in behaviour found in encounters with Chinese patients. In addition to difficulties in interpreting discordant language, in cross-cultural care, the importance of understanding one's own culture has an essential role in achieving a fair clinical interaction (Tervalon et al., 1998; Charles et al., 2006; Jirwe et al., 2009). Self monitoring and critique of practice when encountering people of different culture is part of the process of cultural humility models (Tervalon et al., 1998; Foronda et al., 2014) that are discussed next.

The importance of cultural humility

Participants of congruent cultural background expressed that some Chinese patients may see direct language as impolite. These participants also reported that respect for doctors, was expressed by not wishing to trouble them with problems not thought to be important, and could contribute to a multi-layered cross-cultural care barrier if not recognized by clinicians. Practitioners interpreted politeness and lack of complaints in individuals of Chinese ethnicity as lack of problems and engagement. Although these attitudes could be related to cultural norms, these were interpreted as lack of problems. Other participants attributed this to unwillingness to communicate, or a more reserved attitude. Uncertainty about communication across cultures showed that practitioners feel disempowered, resorting to attitudes that may confer an appearance of certainty and that these can become self-perpetuating increasingly contributing to disparities (Kai et al., 2007). Lack of awareness about difficulties in cross-cultural communication or care, or lack of training in cultural sensitivity or cultural humility create barriers to interpreting needs of patients from different cultural background and can lead to missed opportunities for care (Tervalon et al., 1998; Gerrish et al., 1999). Chronic hepatitis B could add an additional layer of stigma precluding the opportunity to timely diagnose serious complications such as liver cancer (Tran, 2009; Cotler et al., 2012).

The consideration of treating all patients individually, considering the types of barriers that could be present, and the development of cultural self-awareness, are essential steps to tackle these barriers (Kai, 2005; Frenk et al., 2010). However there is no clear path of how to achieve this in a complex and multi-layered health service that continues to perpetuate historical, social and structural barriers to health care equity (Drevdahl et al., 2008; Salway et al., 2016; Nazroo et al., 2020). Although cultural competence training has been advocated for a long period to circumvent these barriers, there is no consistent agreement to what it entails and a lack of evidence of its effectiveness (Drevdahl et al., 2008; George et al., 2015). This ambiguity may contribute to the contradictory influence in effecting changes in health inequalities (Tervalon et al., 1998; George et al., 2015); and it could at times increase inequalities by increasing assumptions about culturally associated attitudes (Tervalon et al., 1998; Drevdahl et al., 2008; Jirwe et al., 2009).

Moving away from the competency model to a more self-reflective framework may provide more sustainable and generalizable concept of equity in providing health care as part of a broader socio-political context (Drevdahl et al., 2008). Tervalon and Murray-Garcia (1998) described the model of cultural humility as the opposite to “othering” cultures and a path to address the manipulation of power subconsciously emerging from a dominant cultural identity that contributes to interpersonal racism. The model advocates training clinicians to focus the encounter on the patient, *“cultivating self awareness and awareness of the perspectives of others”*. In practice, Tervalon and Murray Garcia (1998) advocated for enhancing critical self-reflection and self-observation for medical trainees using video recording. This was described as a training that could help them identify their own deliberate and unintentional patterns of racism, classism and homophobia. The process included making themselves aware of the language used, and self-reflecting on, and addressing one’s own cultural perspective including the concept of professional power over patients. The concept of humility implies a relinquishing of expertise to the patient, bringing in health priorities, beliefs and stressors that may be influencing the therapeutic encounter.

This study did not systematically explore cultural humility or how cultural issues could be addressed by training. However, misinterpreting culturally different attitudes resulting is erroneous diagnosis, misinterpreting non-verbal language and a lack of critical attitude about these errors of judgement were found in the narratives. Cultural humility resulted from searching for a process that is generalizable, that provides life long learning and that results in changing one's own perspective making it applicable to any form of diversity. Cultural humility was proposed by Tervalon and Murray-Garcia (1998) and refined in a recent review of later publications by Foronda et al. (2014). The concept is summarised in the concepts of openness to new ideas, self awareness of own values and limitations, an attitude of flattening of power differentials or 'egoless', supportive interaction with others, and a continued process of self-reflection and critique on one's thoughts, feelings and actions (Foronda et al., 2014). In a recent post-graduate research study a relationship-centred care model was developed using cultural humility principles in NHS diversity training (George, 2017). The study used a tool of situational judgement to evaluate the effect of training in practice. It was found that the most important relationship to examine to improve diversity education was that of "practitioner-self" (George et al., 2019).

It is important to add that in addition to personal development of humility, Tervalon and Murray-Garcia (1998) highlighted the need for the institutions to undergo a similar process of self-reflection and self-critique in order to achieve accountability and competence around equity in health care. This study contributes to understand these through highlighting the service barriers found within a health care setting in England. This understanding provides insight into the barriers that within the clinical encounter contribute to sustain power of professionals and services over patient needs and preferences, perpetuating this way structural barriers. Organizational factors are discussed next.

5.2.4. Organizational resources and conflicting priorities

Health care provided by practitioners in the NHS relied on support provided by the organization and on priorities set by government policies. Lack of resources and gaps in support were recurring themes emerging from the narratives. Organizational barriers in this study were found in the lack of support for the roles of practitioners. There was lack of appropriate equipment for interpretation, lack of printed material either in English or translated into prevalent languages, and lack of awareness of guidelines among front line practitioners. However, these gaps appeared within a more complex organizational context that showed a rapidly changing work environment resulting in increasing workload and mounting uncertainties in regards to responsibilities. Shrinking resources and budget constraints revealing conflicts of interest added to this complex scenario.

Uncertainty about responsibilities

A frequent finding in this study was the lack of clarity about clinical and funding responsibilities. Two particular narratives referred to doubts about who should take responsibility for funding local services for testing and vaccination for hepatitis B in one at risk community and who would be responsible for paying the cost of treatment for patients referred from secondary care. The health care reforms of 2012 created much uncertainty about the functioning of the health service (Checkland et al., 2018). A study of CCGs between 2013 and 2015 demonstrated that different CCGs adopted different methods and strategies making it difficult to negotiate for providers, and generating uncertainty about accountability and governance (Checkland et al., 2016). Participants reported that innovations to address disparities in minority groups and service development were harder to pursue in this decade and some were discontinued with innovative practices being closed down. Although the re-structuring proposed by the Health and Social Care Act (2012) aimed to facilitate increased autonomy and simplification of health services, in reality resulted in a restrictive environment for decision making due to the increased number of bodies involved in such decisions as a consequence of the resulting fragmentation of services (Checkland et al., 2018).

The views from primary care in this study supported the view that these policy and structure changes had a negative impact in continuity of clinical care. Participants described long hours of work, increasing workload for GPs being generated from secondary care and public health, and general unhappiness about the status of working conditions, especially in primary care. Responsibilities about funding for hepatitis B testing and care were unclear. The findings of a study in England that explored views about a program to provide viral hepatitis care in primary care described the concerns of GPs in London and Bradford about this proposal (Sweeney et al., 2015). The study reported that general practitioners were concerned about having the working capacity of providing such service, and expressed the need for specialist clinical assessments and treatments where support for patients can be given more readily. Some also expressed frustration at the lack of consideration of the long-term resources needed for a sustainable service in primary care. Evidence shows that early diagnosis saves lives and the strategy in health care is to offer early testing in order to prevent complications and onward transmission (Locarnini et al., 2015). In addition, cost implications favour early diagnosis by offering timely testing and immunization (Veldhuijzen et al., 2010; Eckman et al., 2011). The proposal of relying in primary care for chronic hepatitis B diagnosis and care might add to the difficulties derived from the changing environment. It could have the undesired effect of increasing the clinical and financial conflicts pushing the condition lower in priority and increasing barriers in access to health care. Baird et al. (2016) in their King Funds' report recommended that policy makers withhold adding responsibilities to primary care in view of the concurrent crisis. The report also recommended increasing support for innovation such as multi-specialist practices and provision of funding in order to respond to the needs of the particular cohorts of patients.

Financial conflicts

From the literature, we learnt that the assumption of financial constrains in patients may constitute a barrier to testing for chronic hepatitis B in a fee for service system (Upadhyaya et al., 2010; Hwang et al., 2012; Chu et al., 2013). Budgetary implications and financial conflicts of interest were also factors emerging from this study. It was clear from the data that these conflicts of interest can influence the priority given to chronic hepatitis B by practitioners. Providing appropriate support for minority patients may conflict with other priorities or even with GPs' salaries as described by participants. The complexity of the barriers that influenced provision of services meant that it was left to services to evaluate their own needs and to request funding for enhanced care from commissioning groups with a limited budget. There were difficulties in addressing the need for a Local Enhanced Service in an area where a rapidly growing migrant population was found to have a high prevalence of hepatitis B. This reflected a lack of understanding of responsibilities for funding. Governing and commissioning organizations such as CCGs, were developing at the time the study was carried out. Increased fragmentation of systems and profound uncertainty about which services needed to be commissioned was described for Public Health bodies after the Health and Social Care Act of 2012 and evidence is still lacking on how this impacted health inequalities (Gadsby et al., 2017).

Participants described low satisfaction in primary care with increasing work resulting from shrinking in capacity, and from increasing demands. Some participants described very long hours of work. It was described that clinicians of older age opted for retirement; others chose to move jobs in search for more job satisfaction. The participant that talked about these issues expressed that despite caring for staff and patients, in the last few years, general practitioners were resorting to these measures triggered by overwork and uncertainty about the future of working conditions, *“hoping that it will get better”*. Early retirement of GPs has been documented as a phenomenon attributed to increasing workload and complexity of referral pathways, and as “*doing an (almost) undoable job*”, among other factors of concern about the future of their profession (Sansom et al., 2016). Increased responsibilities for complex treatments first initiated in secondary care, immunizations and preventive management were described in a Kings’ Fund report as contributing significantly to the mounting pressure in general practice since the recent health care reforms

(Baird et al., 2016). In this environment of organizational crisis, it is not surprising to see that lower priority conditions such as chronic hepatitis B were poorly addressed by practitioners, in turn hindering health care access. Structural barriers however, seemed to influence practice in the longer term. Both the study and literature review showed that national guidelines and clinical pathways were unknown to practitioners with only a few exceptions in this study.

The effect of lack of pathway and promotion of guidelines

Chronic hepatitis B is a condition of low priority in England and is only highly prevalent in some minority groups, but has a significant weight in causes of liver disease in the UK (Williams et al., 2014). The overall message during interviews was one of lack of awareness both of the national guidance and of the high prevalence in groups of Chinese ethnicity that will require application of guideline' recommendations. In addition, uncertainties about clinical responsibilities added to inefficient clinical pathways. Guidelines aiming to address the gap in diagnosis of viral hepatitis, including pathways for diagnosis and addressing health care, were released in December 2012 (National Institute for Health and Clinical Excellence, 2012). In this study, primary and secondary care participants were not aware of the existence of these guidelines. Guidelines have the potential of supporting practice, but without the provision for application and relevance to the clinical situation, these fail to produce changes in practice (Woolf et al., 1999; Cabana et al., 1999).

5.3. What this study adds

This is the first UK based, in-depth qualitative study of perspectives of practitioners that focused on barriers affecting access to health care for chronic hepatitis B by people of Chinese ethnicity. This study contributed to the literature with an understanding of the work of NHS practitioners. The study framed the problem of access to health care for chronic hepatitis B within a national background of low priority within policy and organizational structures that provided insufficient drive and support.

This is the first qualitative study that explores multifactorial and multidisciplinary causes. This particular problem was explored involving different professions and practitioners based in different areas of the health service and from different specialties showing that this is a problem existing across services. Previous studies have explored either general practitioners or key informants specialists in hepatitis (Sweeney et al., 2015; Wallace et al., 2017). In addition, this study was nested within a larger qualitative study that also involved interviews with commissioners and focus groups and interviews with the population (Lee et al., 2017), and that provided unique information that allowed deeper exploration of findings.

This study provided explanations that relate to cross-cultural interactions with people of Chinese ethnicity from practitioners and workers with shared culture, and from other practitioners that had extensive experience with similar populations. The shared cultural views provided the possibility of deepening the understanding of barriers arising from mainstream cultural behaviour and attitudes. This contributed to understanding an interaction with wider determinants that relate to structural and institutional expressions of stigma and racism.

In addition, the study named overlapping practical issues such as providing appropriate support and infrastructure for the clinical communication exchange and better information about the condition. These problems surfaced from narratives in primary care, midwifery and other areas within a regional context but raised the question whether this is a more widespread problem nationally and beyond. The combination of lack of appropriate training in the use of interpreters, poor interpretation infrastructure and of achieving efficient translation in the context of chronic hepatitis B added to already known complexities of using interpreters. Adding to this, there was a lack of support and information for practitioners and patients, and a lack of dissemination and awareness of national guidelines.

This study confirms previous findings that chronic hepatitis B is not well understood by practitioners in England. This condition, where knowledge base is patchy and there are no symptoms, drives a lack of recognition of its significance for long-term health and prevention. These factors add to the problem presented by a condition with serious effects for individuals' health and for public health, in a population that is already known to suffer low access to health services for this and other conditions. Although this may not be a new finding, this study confirms the difficulty in addressing this deficiency and adds to the knowledge of multi-layered factors including institutional and structural barriers.

The candidacy model of access to health care

The candidacy model of access to health care by Dixon-Woods (2006) provided useful concepts to understand factors pertinent to practitioner and system. This study however shows that it is necessary to complement this model factors with other models that address exchange of information and cross-cultural care communication. The domain of adjudication benefits from including elements of shared decision-making that explores a two-way information exchange and deliberation avoiding simplification and *"one-size-fits-all"* in cross-cultural communication (Charles et al., 2006). The cultural humility model (Foronda et al., 2014) has the advantage of supporting a process of self-examination that ensures attitudes changes based on one's own insights can be sustained by continued self-reflective thinking.

Both shared-decision making and cultural humility models address the imbalance of power by ensuring that effective exchange of information provides an adequate scenario for the decisions to be made, that practitioners understand their limitations and that the overall approach is one of negotiation. Negotiation is mentioned in the candidacy model in relation to navigation; however, the domains' names of "adjudication of candidacy" and "offer and resistance" label an imbalance of power without challenging the concept. Resistance is a term used in this model that is at odds with deliberation and agreement that aims to achieve a shared decision. If we consider both shared decision-making and cultural humility models, they describe deliberation or communication between equals based on exchange of information. If this is the case, disagreement may occur rather than resistance. A similar approach can be taken with the term adjudication that infers there is an imbalance of power.

Strengths, limitations and researcher reflexivity that contextualize the contributions of this study are discussed next.

5.4. Strengths and limitations of the study

Qualitative research needs to fulfil certain criteria to be credible and generalizable, and recognition of strengths and limitations complement the framework of research.

5.4.1. Strengths

This is a study of NHS practitioners and key informants. This study has strengths that are discussed here in line with the theoretical and methodological approach.

The study explored qualitative data from practitioners recruited from primary and secondary care, midwifery and health promotion and included participants from nursing and medical professions. Recruitment also included key informants from underserved and migrant communities and health promotion officers both working in facilitating access to services. The participants worked in different geographical locations within the North of England and in varied specialties, had varied length of experience, and were from different age groups, genders and ethnicities. This allowed for different viewpoints and experiences to generate sufficient potentially generalizable data. It also allowed identification and comparison of cross cutting themes.

The view of practitioners that care for mostly migrant populations can be different from views of practitioners caring for mostly majority population and both these participants were included in the study, providing also data to examine experience that may miss barriers from different contexts. In addition, early career practitioners may consider different barriers than experienced and senior practitioners giving a wide range of views from which to draw data.

Relationships between different areas of services were revealed that added to the understanding of the context of barriers in access. Participants from different areas frequently referred to other areas. Primary care practitioners frequently mentioned the relationship with secondary care, and those working in the community their relationship with primary and secondary care. This provided ample data to generate interpretive results that had multiple sources and to understand wider organizational factors. Although in general other areas were mentioned as part of the patient journey, conflicts and imbalances were evident in many of the narratives that pointed to unaccounted barriers to access to health care.

The richness of in depth, qualitative studies reside in providing explanations for phenomena identified previously. There is a plethora of evidence in the literature of health care access studies that mostly address population barriers, those that have language barriers and those with deprived socioeconomic background. This study provides a view of barriers based on health care practitioners and key informants account of their experience. This approach can provide a particular view of these inequalities; in particular exploring the view of culturally congruent practitioners provided an understanding of the barriers and how they are relevant to access to health care.

Theoretical models provided a guide for categorising and interpreting findings and contributed to the understanding of inequalities originating in services. The candidacy model by Dixon-Wood (2006) helped categorize particular functions of practitioners such as identifying risk for chronic hepatitis B and offering of services such as testing, referral to hepatitis B services and immunization of contacts. Understanding factors affecting the clinical interaction with patients was also helped by the use of other models. Shared decision-making models helped identifying difficulties during the exchange of information and understanding decisions being made without consulting with patients (Charles et al., 1999). Cultural sensitivity and humility models helped distinguish other potential barriers affecting the clinical encounter. For example, assumptions made about patient understanding, practitioner understanding of their own communication barriers and self-reflection about their own cultural beliefs and attitudes (Jirwe et al., 2009; Foronda et al., 2014). The study was based in an understanding that practitioners' roles evolve according to demands; therefore, factors influencing these roles may also change. In this context, Dixon-Woods (2006) model allowed the exploration of wider factors determining accessibility of services. Low permeability of services emerged as barriers in chronic hepatitis B compounding system-based barriers. The models also helped to categorize the key findings.

This study was carried out in the context of a wider study that incorporated qualitative studies of the population and of commissioners and public health participants. The different arms provided a background and helped guiding the practitioners' study; they provided data to help understand findings and added strength to the outputs. In addition, participatory workshops with community and relevant practitioners that were carried out to draw on the discussion of findings for the whole study contributed to the interpretation of the data.

For this study, I conducted all the interviews and analysis providing a consistent approach throughout collection of data. I was aware that I am a peer or insider researcher and this can represent strength in the study by being able to explore experiences and attitudes further. The advantage of being a clinician that works in the area and has experience with underserved populations resides in a deeper understanding of the situation; and although these can also represent limitations; awareness of these helped addressing them.

5.4.2. Limitations

This study identified a number of issues that interrelate and show that mechanisms can be complex. The complexity of barriers that exists at multiple levels cannot be comprehensively identified in one study. Although the results describe barriers in three specific areas, the individual practitioner, the interaction with patients and organizational barriers, these are not exhaustive. Many other barriers that may exist may not have emerged in this study and cannot be excluded.

The importance of applicability of findings cannot be sufficiently emphasized in the area of access to health care. Although this study recruited a significant number of different participants, the number is small and regionally circumscribed; the findings will tend to be context specific, and specific findings may not be generalizable to other contexts in the UK or worldwide. In addition, the participants recruited may have agreed to interviews because the subject was relevant or of interest to them, providing a biased view of people that look after underserved populations and are interested in responding to health inequalities.

In addition, the collecting of data was done through semi-structured individual interviews; these may not be able to explore interactions and exchange of ideas between practitioners that could be achieved from focus groups for example. Although interviews are ways to explore in depth individual accounts, they are descriptions and not observations; they contain views that may not be a full representation of the actual process but a subjective interpretation of such process. The limitations of interviewing in public places in some cases and via telephone in other mean that interviewees' predisposition to share experiences could have been limited.

Mentioned as a strength, the issue of being an insider researcher can also include limitations. Blind spots and biases are a risk to be considered when undertaking the study and in the interpretation of findings. As a specialist in the subject, I found myself blind to factors not essential in my practice but that were important factors requiring exploration. These emerged when participants emphasised their importance, for example patient's priorities unrelated to health but that could have an impact on accessing health care. The limitations of in-depth exploration of these areas may be difficult to assess.

During the interviews, a neutral stance and prompting for explanations were used, but this may not fully avoid bias or power differentials. Reflective practice, review of literature and discussion with supervisors and with other researchers were useful in recognizing areas of difficulty and address personal tendencies or biases during collection of data, analysis and writing but full coverage of all limitations cannot be fully guaranteed.

5.5. Researcher reflexivity

Researcher reflexivity is essential in qualitative research as it helps addressing subjectivity and tendencies of the researcher that can have an influence in the research approach, findings and interpretation of data as explained in section 3.1.3. The role of a peer researcher and personal interests and biases were acknowledged; and an understanding of the context in which the study has been conducted helped to recognize transferability to other contexts. Reflexivity has been incorporated throughout this document. In this section, I intend to make a final recognition of those elements that can affect research and can compromise credibility and truthfulness of the findings analysis and interpretation.

5.5.1. Acknowledging the role of the insider researcher

Undertaking a qualitative study of peers required reflecting on the influence of the researcher (Spradley, 1979). Researcher influence was acknowledged during this study and addressed by adopting an impartial approach to interviewing. The relationship of trust during interviews might be difficult if participants anticipate feeling challenged by the interviewer who is a specialist in the subject. This particular difficulty was not obvious during interviews but might have been a factor in declining invitations to participate.

During interviews, I adopted an impartial position within the possibilities of the interaction. Assumptions about participants’ narratives or experiences were avoided and prompts helped to expand into what emerged when familiarity with the response was identified. This approach provided also a platform for exploring participants' experiences and revealed that views can be very different to the one the interviewer may assume based on their experience.

Reflectivity was focused on my own absence of neutrality when interviewing peers that had previously demonstrated differing priorities. Potentially these differing views enriched the findings by providing diverse points of view on the issue of equity of health care. My concerns emerged during interviews that were carried out with practitioners I interacted previously during an outreach project. On one occasion a participant's critical attitude resulted in a reactive feeling that threatened maintaining a neutral position, however the participant acknowledged the effect his comment had had, which allowed me to resume and adopt again an impartial approach. The following example shows the reflective account where I acknowledge what feeling surfaced and how this could have affected the interview process, this helped to be aware of my own reactions in future interviews.

"I interviewed a participant who knew of a community testing project I undertook 6 years previously. This influenced the interview because the participant had previously worked in a GP surgery that not been happy about the letter I wrote to them during the project. At the time, I was asking for GPs to consider actions but was not aware of the limitations primary care had in terms of funding for vaccinations when these were not indicated (i.e. there is no proved close contact). One of the answers during the interview was uncomfortable for me, perhaps because I did not understand the actual purpose of the respondent answers and felt personally criticized. The respondent noticed and clarified, I was

able to continue the interview without major problems although I felt somehow inhibited. However, this was one the richest interviews, because of the practitioner’s experience with the Chinese community and in training primary care peers.“

Equally during analysis, regularly questioning the influence of own tendencies and guaranteeing further exploration was achieved by discussion with supervisors and peer researchers. Reflecting on own practice and on assumptions that might have emerged during the study was maintained throughout the writing stage. For example, the priority given to chronic hepatitis B was influenced by many years of practice in the specialty. I had had experiences of missed diagnosis that could have prevented morbidity or even death. In addition, my experience in outreach showed that when people were linked to services after decades of being diagnosed they were grateful they had been made aware that they needed health care input and treatment.

Although these are important experiences, they address a discrete population, suffering from one particular condition and that would be expected to attend a particular specialist service once diagnosed. However, the population outputs from the wider study showed that not all participants chose to access health services and many did not find the process was beneficial for them for many reasons. These findings helped shift the focus in my mind. From that point onwards, these assumptions were less problematic and a more balanced view was acquired, incorporating the concept of patients’ preferences into the discussion and how practitioners could manage this.

In a final point, I perceived that the candidacy model described patient input as resistance (Dixon-Woods et al., 2006). I find this term biased in terms of power balance, stating that patients resist rather than choose. The candidacy model assumes that power is with the professional. Informed choice or patient preference may be a better term to describe the domain of resistance in the candidacy model.

5.5.2. Acknowledging personal interests and experiences

Addressing the influence of personal and professional interests in qualitative research can help minimize biases and blind spots when defining the research question, while doing interviews and during the analysis of data (Ritchie, 2014). It was important to understand how my personal and professional experience could influence my approach to the research and I briefly described this in Section 3.1.3. In addition, I reflected about being a specialist in the above section and on the limitations section in this Chapter.

In the infectious diseases field, underserved groups are frequently encountered. These are groups with recurrent barriers to accessing necessary health care. These challenges had prompted service improvement projects using a microsystem model in the department to try to address these (Nelson et al., 2008). I learnt during these projects that not all practitioners or administrative workers perceive these challenges; that there is varied depth of understanding and different attitudes towards changing system barriers. The experience of system improvement was useful to understand the complexity of mapping the patient journey. It revealed the lack of understanding of many health service workers of such complexity. These experiences have been helpful to understand the background of this study. They also revealed that the gaps are not easy to address when power imbalances are not being addressed.

Examples of reflexivity about other characteristics

It was clear to me that my experiences as a migrant could be relevant to the study; in my case being aware of certain barriers to access to services or even of communication difficulties.

"As a migrant, I think there is an important influence of my experience in understanding a different system. I can see things that are otherwise invisible to workers that had not had the experience of different systems. I previously had to adapt and change previous learned behaviour in order to access service. I had to learn to communicate without being misinterpreted. I notice that this is not a major issue in primary care if the setting has majority of migrant patients and health care workers are experienced in facilitating access, but may be a barrier in settings where there is less experience."

These experiences could be an advantage in awareness but could also generate preconceptions by prioritizing failures or gaps and missing out in understanding the successful provision and delivery of services. Being aware of this possibility generated the objective to balance the recognition of effective health care without ignoring the gaps.

5.6. Implications for policy, practice and further research

The following sections will explore the recommendations that emerge from this study. Exploring access to health care factors originating in practitioners and services helped understanding factors originating in, and affecting health care practice. Following are the recommendations for informing policy, professional education and research.

5.6.1. Health care practice recommendations

Health care practitioners are ideally placed to offer early diagnosis to populations with high prevalence of chronic hepatitis B such as migrants of Chinese ethnicity. The barriers observed include communication and cross-cultural issues and a low priority of the condition that will be discussed in policy implications. These long-term problems emerged in a challenging context resulting from wide health system reforms that has produced uncertainty and increased workload.

Communication issues

Two major areas of communication have implications for practice: cross cultural care training and evaluation, and the training and evaluation of the use of professional interpreters. In addition, standardized basic information about chronic hepatitis B accessible to any practitioner and patient is needed.

Cross-cultural training using cultural humility models

Current training in the NHS is aimed to understand Equality and Diversity. This involves online modules that describes current regulation, and gives examples where discrimination can occur, but does not help to evaluate behaviour changes. Models that could potentially result in effective change and that can be evaluated are not widely disseminated.

The cultural humility model aims to produce changes in the individual and the organization that can be applied to all forms of diversity and it does not focus just on ethnic diversity. The model employs general mechanisms that generate continuous personal change, by adopting a self-assessment stance on own attitudes and behaviours. There is a recent study providing training and evaluation tools for diversity education; this is discussed in a doctorate thesis and suggests using situational judgement tests to assess the effects of diversity training in NHS practitioners (George, 2017). More recently, the University of Sheffield has started offering a longer-term training based in cultural humility models called SEEDS (Seeking Educational Equity & Diversity) that encourages self-reflection and continued learning.

These models and tools for evaluating change should be considered for individual and organization changes to improve equity in access to health care services.

Training in the use of interpreters

The study confirmed that using professional interpreters is a complex strategy that is not addressed adequately. Language discordance even with the use of interpreters could give rise to clinical risk, and to misunderstanding of patient preferences and of the impact of treatment. There is a clear need to be able to check that the information had been understood by interpreter and patient, and that information provided by patient is relayed appropriately. The consequences of poor interpretation or inadequate use of interpreters can result in serious clinical errors and misunderstanding of treatments and other management strategies.

Most practitioners in this study had not received training. Consideration should be given by organizations to provide training to all workers that need to make use of this service as a clinical governance measure.

Addressing chronic hepatitis B in practice

There is a need to address the lack of current strategy to address chronic hepatitis B systematically in the health service, in order to offer an equitable service to those affected. In the study, the context appeared as one lacking in training of practitioners, among a national low prevalence of hepatitis B, a low priority in policy and reliance on programmes of local or speciality-driven testing. The result was that individual practitioners were left to respond to this need of populations without the appropriate drive from policy and commissioning, and without the knowledge required. Although I did not set to explore practitioner knowledge of chronic hepatitis B, it was clear from the data that awareness of risk factors and knowledge of the condition and the prognosis was low. Practitioners in primary care highlighted that there was too much to consider during clinical encounters and hepatitis B was low in clinical priorities unless there were abnormalities or symptoms. Prioritising silent conditions that may affect discrete cohorts of patients may require a drive from organizations and policy. In addition, raising awareness among practitioners of the need for early diagnosis, and the clinical pathways could be helpful.

The narratives offered examples of limited local initiatives to offer testing to discrete groups found to have high prevalence of the condition. These practical initiatives clearly needed support from the commissioning bodies as they represented a response to a significant health need and are of low cost. But lack of awareness at commissioning level and uncertainty about responsibilities for care and funding threatened this. This is discussed in policy implications.

Individual practitioner roles in the response to needs of discrete populations could benefit from electronic reminders as shown by Hsu et al. (2013), and from institutional support in the form of supportive information for both patients and practitioners as reported by practitioners in this study.

5.6.2. Work context factors

Organizations must be aware of the impact of system changes and ensure working challenges are addressed to facilitate the continuous provision of fair and equal health care services. Collaborative working between different areas of the system and institutions is patchy and communication may be poor or absent, causing dissatisfaction in practitioners and patients from poor care provision. Increasing communication and clarifying pathways and responsibilities with increased collaborative working between primary and secondary care and community services and centres may help resolve some of the conflicts demonstrated in this study.

In addition organizations should be aware of the impact of restrictive clinical pathways on equity of access to needed health care for underserved populations. A review and critique of mechanisms of access to services, using processes guided by cultural humility models could help address some of these barriers.

5.6.3. Policy implications

Identification of national gaps in addressing prevalent conditions in minority populations is essential to facilitate improved practice and decrease inequities in health.

Low priority of the condition and discriminatory practice

There is a national commitment to address liver disease in all populations at risk due to the increasing trend in liver mortality (Department of Health, 2010). From this study emerged that chronic hepatitis B has not been addressed as a priority in commissioning despite being among the causes of liver disease. Excluding chronic hepatitis B from these programs reflected the persistence of structural racism and further contributed to it. Facilitating programmes of testing for viral hepatitis in minorities affected by it could help bypass these barriers. Commissioning programmes need to be considered with an open mind, this usually involves low numbers in comparison to other conditions, therefore overall low cost, but the health benefits are significant.

This study contributed to understanding that the barriers in practice may be many and the importance of clear health policy was among them. In addition, there was uncertainty about responsibilities of whether this was a clinical commissioning issue or a public health issue which needs clarification. A practical guide for practitioners and commissioners to improve practice in an effective way and promote equity in health care for minority groups is necessary. Importantly, organizational measures that marginalize conditions that mostly affect minority racial groups need to be seen as the exerting of discrimination by service-providers (*Equality Act 2010*).

5.6.4. Professional education recommendations

Two areas could be addressed in medical education; these are related to cross cultural communication and how to address prevalent conditions in underserved groups.

Effective cross-cultural communication

As discussed above, enhancing cross-cultural communication practices requires exercising critical insights about our own limitations and biases. Generally, training in medicine was lacking on these areas although communication skills were reportedly being given higher priority. Nursing training has traditionally been more focused on providing cross-cultural training using cultural competence models (Jirwe et al., 2009). The effectiveness of this type of training however, was variable and difficult to evaluate (Drevdahl et al., 2008; George et al., 2015). Since the barriers can be multi-layered, an approach that focuses on practitioners' personal development and change rather than in acquiring more information or addressing single factors in education could be a more effective option. Robust evaluation of this type of education and training could provide the evidence that is lacking in this area.

Silent conditions prevalent in underserved minorities

Although this study focuses in chronic hepatitis B and Chinese populations, the generic aims are to highlight the main barriers that can be relevant in professional education and that may be applicable to similar barriers in other conditions or populations. Curriculums may be vast and the need to incorporate frequently seen conditions may act as a deterrent to incorporate conditions that are not prevalent in the region or country. Awareness that both practitioners and patients may ignore some conditions that can have a serious impact in health is essential and wants to be incorporated in training and education; but with the caution about increasing stigma if certain populations are associated with certain conditions.

The experience of participants revealed that chronic hepatitis B was only on lists of differentials for abnormalities of liver tests, and in tests provided to diagnose sexually transmitted infections. The more recent developments in management of chronic hepatitis B must reflect into medical education in the same way that has done for HIV. It is a highly prevalent condition worldwide with serious consequences and that we will continue to see in areas of low prevalence such as the UK, particularly affecting underserved groups.

The importance of addressing this and other less pressing conditions, needs to be part of curricula that aim to form and inform professionals working with an increasingly multicultural and diverse population, and contributing to making service-provision equitable and fair.

5.6.5. Implications for further research

There are research implications related to professional training and education, which in turn may have an impact in practice and policy. The evidence points to service barriers in the current model of care, primary care based models of care are being proposed in England (Sweeney et al., 2015) but effectiveness data for such model is lacking.

Equality, diversity and inclusion training can be a key factor in improving cross-cultural health care provision. This study raises issues about how to best put in practice the wealth of research in cross cultural care. Sufficient evidence of interventions that work and are sustainable in asymptomatic infections is needed. Currently in the NHS and in Higher Education there is a mandatory requirement to be trained in equality and diversity. The basis of this mandate is based in the latest legislation (*Equality Act 2010*). This key area could play a role in facilitating improved access services for underserved groups including migrants. However there is little research evaluating the effects of training. In addition, the type of training available in equality and diversity is variable and there is a lack of evidence that this training has the desired effects. Application and evaluation of methods for training that can effectively address equality, diversity and inclusion in NHS institutions for professionals and other workers is needed.

5.7. Conclusion

This is the first in-depth study carried-out in England that provides insight into service and practitioners' factors that affect access to health care for chronic hepatitis B for people of Chinese ethnicity residing in England. Health care practitioners struggle to facilitate access to health care for minority populations at risk of chronic hepatitis B due to barriers that exist at different levels of the pathway. Factors hindering effective communication and safe practice need addressing by enhancing shared decision-making skills, communication skills and training in the use of interpreters. There is a clear need to effectively enhance cross-cultural communication with individuals that will help address patients' preferences and needs, and skills related to cultural humility could provide a measurable and sustained training to support the process.

Organizational factors play a key part in supporting access pathways for chronic hepatitis B that affect underserved minority groups. There is a clear lack of dissemination of accessible access pathways, lack of appropriate information for practitioners and patients and inconsistent provision of appropriate infrastructure for language support. Guidelines alone fail to effect improvement in practice. Awareness by health care organizations and policy makers of the effect of these in perpetuating structural racism should be made priority and aligned with preventing racial discrimination as described in the Equality Act 2010.

Overall, this study has provided evidence that much could be done to improve access to appropriate and effective testing and healthcare for a low priority but serious clinical condition, for a minority community, which is disproportionately affected.

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7. Appendices

1. Background notes

    A1.1 Theory models relevant to the study

    A1.2 Brief history of HBV discovery and developments

    A1.3 Hepatitis B and C testing: people at risk of infection [NICE Guideline PH43]

2. Protocol for literature review

    A2.1 Databases used and definitions

    A2.2Literature review search protocol

    A2.3 Excluded practitioners papers and reason for exclusion

3. Practitioner study topic guides

    A3.1 Topic guide for individual interviews

    A3.2 Interview guide

    A3.3 Demographic groups guide

4. Analysis: linking themes

5. Ethical approval documents

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    A5.2 Information sheet

    A5.3 Consent form

6. Publications and presentations

A6.1 Publications

A6.2 Presentations

APPENDIX 1 **Background notes**

A1.1 Brief history of HBV discovery and developments

World War 2:

The recent history of discovery of hepatitis B extends probably to times when serum or blood from one person affected was transferred to another who was susceptible causing them to develop jaundice. Early studies done during the II World War identified a form of hepatitis happening in soldiers that received blood transfusions and developed jaundice days or weeks after. To make a distinction with the well-known “infectious hepatitis”, which was orally acquired (now known as hepatitis A), this new form was called “serum hepatitis” (MacCallum, 1948).

Discovery of the virus:

Later studies in “post-transfusion hepatitis” (Senior, 1965) lead to the discovery of the Australian antigen (now known as surface antigen) in an aboriginal affected by leukaemia in 1965 (Blumberg et al., 1965), although the nature of such antigen had not been elucidated. Further studies showed that the Australian antigen could be used as an indicator to prevent post-transfusion hepatitis by using only blood free of the antigen (Senior et al., 1971). When the virus was isolated in 1970 the infectious nature of post-transfusion hepatitis was confirmed (Dane et al., 1970).

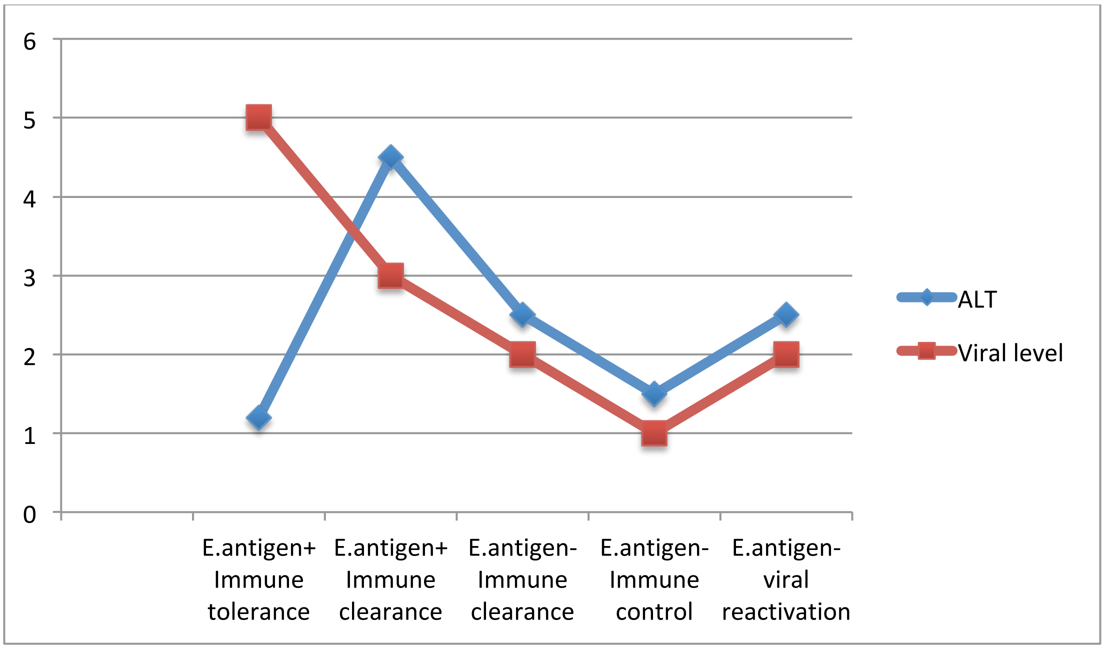
Relation with liver cancer and understanding of physiopathology:

During the 1970’s the association of the hepatitis B virus with liver cancer was established (Blumberg et al., 1976); and in the early 1980’s hepatitis B vaccines had been developed (Szmuness et al., 1980; Beasley et al., 1983) that effectively prevented the infection.

After this earlier progress and since the early 1980’s, the understanding of physiopathology and the development of treatment were protracted. The development of laboratory techniques in virology and histopathology provided a bridge to accelerate understanding during the 1990’s. It was only in the early 2000’s that the pathology of chronic hepatitis B as it is currently understood began to impact clinical management (Yim et al., 2006). Access to advanced laboratory techniques in the late 1990’s, such as polymerase chain reaction or PCR that detected and quantified the virus, and histological examination of the liver that determined stages of the disease, permitted a better understanding of the progressive pathology of the disease, the consequences of inflammation in the different phases permitting the identification of patients requiring treatment.

The phases of chronic hepatitis B:

The understanding of physiology that guided indication for treatment was described in the early 2000’s (Yim et al., 2006) and consisted of four phases, these were called immune tolerant, immune clearance, immune control and immune escape. These phases were based in vertically acquired chronic hepatitis B but can be identified in most infections, only with different durations. This graph explains the definition of the phases as previously understood. Some studies of cross cultural communication in chronic hepatitis B have used this understanding (Wallace et al., 2011).



However, even this new approach has been changing in the last 5 years. The phase immune control or inactive carriers (now low replicative) is still considered not amenable to available treatments (Gish et al., 2015). Not providing treatment to patients in the initial high replicative phase previously called tolerant phase is controversial (Kennedy et al., 2017), because it is recognised that low grade inflammation may exist and it could be the cause of progressive liver disease or liver cancer. The initial phase has now been considered to have either high replication with low inflammation or with chronic hepatitis (Gish et al., 2015).

Development of treatment:

Studies of interferon alpha during the 1990's for treating chronic hepatitis B describe many side effects including psychiatric effects and high cost, however it can provide a time limited treatment with a sustained viral response in selected patients (Wong et al., 1993). Improved in side effects and response, pegylated interferon alpha succeeded interferon alpha in 2001 and continues to be a first line treatment if there are no contraindications (European Association for the Study of the Liver, 2012). When HIV treatment started to be used in 1997, it was noted that Lamivudine, a nucleoside inhibitor, also treated HBV (Benhamou et al., 1996) and this became to be used for chronic hepatitis B. Newer antiviral drugs were licensed in UK, in 2006 for Entecavir and 2007 for Tenofovir. These suppress viral activity, preventing and even reversing liver cirrhosis, and reducing the rates of liver cancer (Lin et al., 1999; Lok et al., 2009; Chang et al., 2010; Marcellin et al., 2013). When the disease is advanced, providing clinical surveillance in people with higher risk of developing liver cancer has meant that small lesions can be picked up at an early stage and can be treated with surgery and liver transplantation (Gordon et al., 2014).

Overall, chronic hepatitis B has been a difficult infection to understand due to the complexity of interaction with the host (humans), the protracted development of treatment, and probably the fact that is silent and affects underserved populations, therefore activism to urge research has been absent.

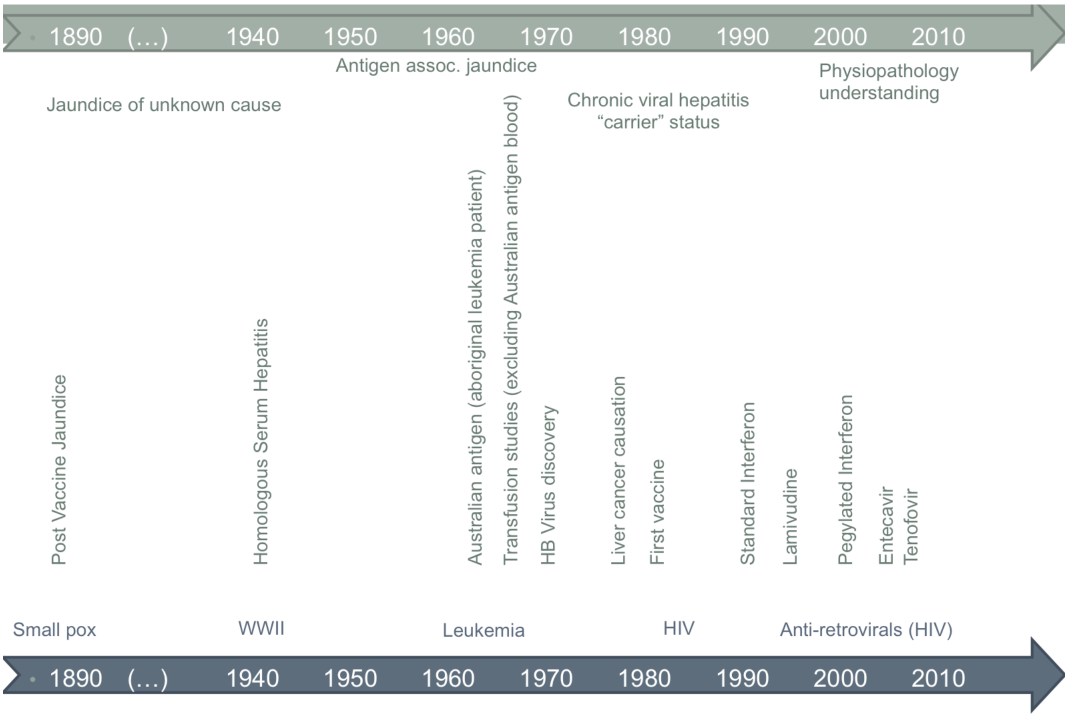


Figure A1.1 - 120 years of history in the discovery of chronic hepatitis B and treatment

A1.2 Hepatitis B and C testing: people at risk of infection

(From NICE guidelines PH43, first published December 2012)

Whose health will benefit?

In the UK, the majority (95%) of new chronic hepatitis B infections occur in migrant populations, having been acquired perinatally in the country of birth. In contrast, approximately 90% of chronic hepatitis C infections are seen in people who inject drugs or have done so in the past.

Groups at increased risk of hepatitis B compared with the general UK population include:

- *People born or brought up in a country with an intermediate or high prevalence (2% or greater) of chronic hepatitis B. This includes all countries in 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:*
- *People who have had multiple sexual partners*
- *People reporting unprotected sexual contact in areas of intermediate and high prevalence)*
- *People presenting at sexual health and genitourinary medicine clinics*
- *People diagnosed with a sexually transmitted disease*
- *Commercial sex workers.*

- *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.*

A1.3 Access to healthcare models relevant to the study

Access at the interface of health care services (Levesque et al., 2013)**.** Access is defined as the opportunity to have health care needs fulfilled.

	Services dimensions:	**Health care needs**	Corresponding person abilities:	
Transparency Outreach - Screening Information	Approachability	**Perception of needs** and **desire for care**	Ability to perceive	Health literacy Health beliefs Trust and expectations
Professional values norms, culture, gender	Acceptability	**Health care seeking**	Ability to seek	Personal and social values, culture, gender, autonomy
Location, opening hours, appointment mechanisms	Availability and accommodation	**Health care reaching**	Ability to reach	Living environments Transport Mobility Social support
Direct costs Indirect costs Opportunity costs	Affordability	**Health care utilisation:** - Primary access - Secondary access	Ability to pay	Income Assets Social capital Health insurance
Technical and interpersonal quality Adequacy Coordination and continuity	Appropriateness	**Health care consequences:** - Economic - Satisfaction - Health	Ability to engage	Empowerment Information Adherence Caregiver support

Cultural sensitivity statements that reached consensus in Delphi exercise with experts (Jirwe et al., 2009)

Personal attributes

To have a humane outlook

To show respect towards others

To be compassionate towards others

To respect differences between people from different cultures

To be willing to provide culturally congruent care

To be flexible in approach

To be open to cultural difference

To have the ability to empathise

To be reflective

To have the confidence to ask questions

To be perceptive

Self-awareness

To be aware of the risk of perceiving one's own culture as 'right' and other cultures as 'different'

To be aware of one's own reactions to people from different cultural backgrounds

To be aware of one's own prejudices

To be aware of one's own values and frame of reference

To be aware of one's own views on health, illness, ill health and well-being

To be aware of the risk of judging other cultures on the basis of one's own culture

To be aware of one's own culture identify, to understand people from other cultures

To be aware of the background factors that have shaped one's own cultural traits, to be aware of one's own stereotypical views of people from other cultures

To be aware that as a nurse one is in a position of authority

To be aware of whether one has individual or group oriented values

APPENDIX 2 **Literature review**

A2.1 Databases used and definitions

Name	Definition	Reason
ASSIA	Applied Social Sciences Index and Abstracts is an indexing and abstracting tool covering health, social services, psychology, sociology, economics, politics, race relations and education.	Aim to capture sociological publications that may not appear in medical databases
CINAHL	The Cumulative Index to Nursing and Allied Health Literature provides indexing of the top nursing and allied health literature available including nursing journals and publications from the National League for Nursing and the American Nurses Association. Literature covers a wide range of topics including nursing, biomedicine, health sciences librarianship, alternative/complementary medicine, consumer health and 17 allied health disciplines.	Aim to capture nursing publications especially those addressing transcultural care and that may not be found in medical databases
EMBASE	*Excerpta Medica* Database is a biomedical and pharmacological database of published literature designed to support information managers and pharmacovigilance in complying with the regulatory requirements of a licensed drug.	Extension of medical database with a pharmacological orientation (no longer supported)
MEDLINE (Ovid)	Produced by the U.S. National Library of Medicine (NLM), Ovid MEDLINE covers the international literature on biomedicine, including the allied health fields and the biological and physical sciences, humanities, and information science as they relate to medicine and health care. Information is indexed from approximately 5,600 journals published worldwide. Also included are the In-Process & Other Non-Indexed Citations and Epub Ahead of Print databases.	Main medical database where the majority of publications were found
PsycINFO	PsycINFO contains citations and summaries of peer-reviewed journal articles, book chapters, books, dissertations, and technical reports, all in the field of psychology and the psychological aspects of related disciplines, such as medicine, psychiatry, nursing, sociology, education, pharmacology, physiology, linguistics, anthropology, business, and law.	Aim to capture publications with a psychological orientation that may not appear in other medical databases
Web of Science	Web of Science is a multidisciplinary research platform, which enables simultaneous cross-searching of a range of citation indexes and databases; it provides deep coverage and comprehensive indexing of the journals, books, and proceedings in the Social Sciences and Arts & Humanities. It was previously known as Web of Knowledge.	Aim to cross search humanities and sociological publications that may not appear in medical databases

A2.2 Literature review search protocol

1. Population: “Chinese”, “Asian continental ancestry group”, “Asian Ancestry”, “Far East Asian”, “Korean”, “Taiwan or Taiwanese”, “Malaysia or Malaysian”, “Asian”, “East Asian”, “Singapore”, “Vietnamese”, “Laos or Laotian”, “Cambodia or Cambodian”
2. Health care access: “Barriers”, “Access to Health Care” (or healthcare), “Health services accessibility”, “Healthcare disparities”, “Patient acceptance of healthcare”, “Health Knowledge, Attitudes, Practice” or “barrier$ to health”, “Health behaviour” or “Attitude to health”
3. Hepatitis B: “Hepatitis B, Chronic”, “Hepatitis B”, “HBV” or “Hepatitis B Virus”

   NOTE: Terms such as migrants, migration, testing, treatment, were found to restrict the number of results found, therefore were not utilized in the final search strategy.

A2.2.1 - Example of search terms string used in Medline

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE(R) and Ovid OLDMEDLINE(R) <1946 to Present>
Search Strategy:

----

1 Vietnamese.mp. or exp Asian Continental Ancestry Group/ (44890)
2 Chinese.mp. or Asian Continental Ancestry Group/ (162800)
3 Korean.mp. or Asian Continental Ancestry Group/ (55388)
4 Taiwan/ or Asian Continental Ancestry Group/ or Taiwanese.mp. (60012)
5 Laos/ or Laotian.mp. (1347)
6 Malaysia/ or Malaysian.mp. (11047)
7 Cambodian.mp. or Asian Continental Ancestry Group/ (37706)

8 Asian.mp. or Asian Continental Ancestry Group/ (80680)
9 East Asian.mp. or Asian Continental Ancestry Group/ (42588)
10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (250954)
11 Health Services Accessibility/ or Access to health.mp. or "Patient Acceptance of Health Care"/ (82957)
12 Health Knowledge, Attitudes, Practice/ or barrier$ to health.mp. (73646)
13 Health Behavior/ or Health behavio$.mp. or Attitude to Health/ (103260)
14 Healthcare disparit$.mp. or Healthcare Disparities/ (7703)
15 11 or 12 or 13 or 14 (241571)
16 10 and 15 (7657)
17 exp Hepatitis B/ or exp Hepatitis B, Chronic/ or hepatitis B.mp. (77030)
18 exp Hepatitis B virus/ or exp Hepatitis B/ or HBV.mp. or exp Hepatitis B, Chronic/ (60017)
19 b hepatitis.mp. (3341)
20 17 or 18 or 19 (80423)
21 16 and 20 (148)

A2.3 Methodological process used for the wider literature review

Methodological rigour was examined with a questionnaire that provided a scoring system as described below. This was designed during research team discussions with advice from Prof. Sarah Salway (Senior Social Scientist).

Methodological rigor (general)

AND

Methodological rigor (consideration of ethnicity and diversity)

Methodological rigor (Yes=1, No=0 for each of the below)
1. Are the methods used appropriate to the objectives?
2. Is there evidence of researcher reflexivity/consideration of validity?
3. Is there sufficient data (depth, detail, richness / sample size) to appraise?
4. Is the source of data clear and issues of bias adequately dealt with?
5. Are the conclusions appropriately based on the data?
6. Is adequate attention given to the social/economic context in which health outcomes are measured and health behaviours occur?
7. Is diversity between groups/ethnicities acknowledged and addressed in the analysis?
8. Is diversity within each group acknowledged and addressed in the analysis?
High= 6-8 Medium= 4-5 Low= 0-3
Is there any other issue related to design or conduct of this study that raises concerns about the inclusion of evidence from this study? If yes – refer to second researcher - paper to be excluded if agreement

The question that scrutinized the ethnicity criteria was:

7. "Is diversity between and within groups / ethnicities acknowledged and addressed in the analysis?"

Example of paper scoring during the wider study literature review

Ref	Meth.	**7.1.** Meth.	Place	Rich?	1	2	3	4	5	6	7	8		
E Yang, C Cheung, S So, ET Chang, S Chao 2013	Qual: SSI	Interviews: barriers to prevention and counselling and reasons for low knowledge in 16 obstetricians and 17 perinatal nurses	Santa Clara County, California	yes	1	1	1	0	1	1	1	0	6 = high	IN
D Chu, A Lok, T Tran,… R Kim 2013	Survey	217/270 Asian American PCPs with ≥25% Asian patients in their practice	New York, Los Angeles, San Francisco, Houston, and Chicago	yes	1	0	1	1	1	1	1	0	6 = high	IN

A2.4 Excluded practitioner papers and reason for exclusion

First author, Year **Locality, Country**	**Method**	**Aim**	**Participants/ response rate**	**Conclusions**	**Exclusion reason**
Guirgis,[i] 2010 **Kogarah, Australia**	Cross sectional survey	Knowledge of viral hepatitis	123/280 GPs 44%	Good knowledge of testing but lack of awareness of liver cancer relation to HBV	Focused mainly on knowledge of disease, not sufficient data for analysis.
Robotin,[ii] 2013 **Sydney, Australia**	Cross sectional survey compared 1st and repeated attendances to CME seminars	Knowledge of viral hepatitis	130 GPs 69 one attendance and 61 repeated attendances	Low knowledge score, no improvement after repeated seminar attendance	Focused mainly on knowledge of disease, methods not congruent with aims.

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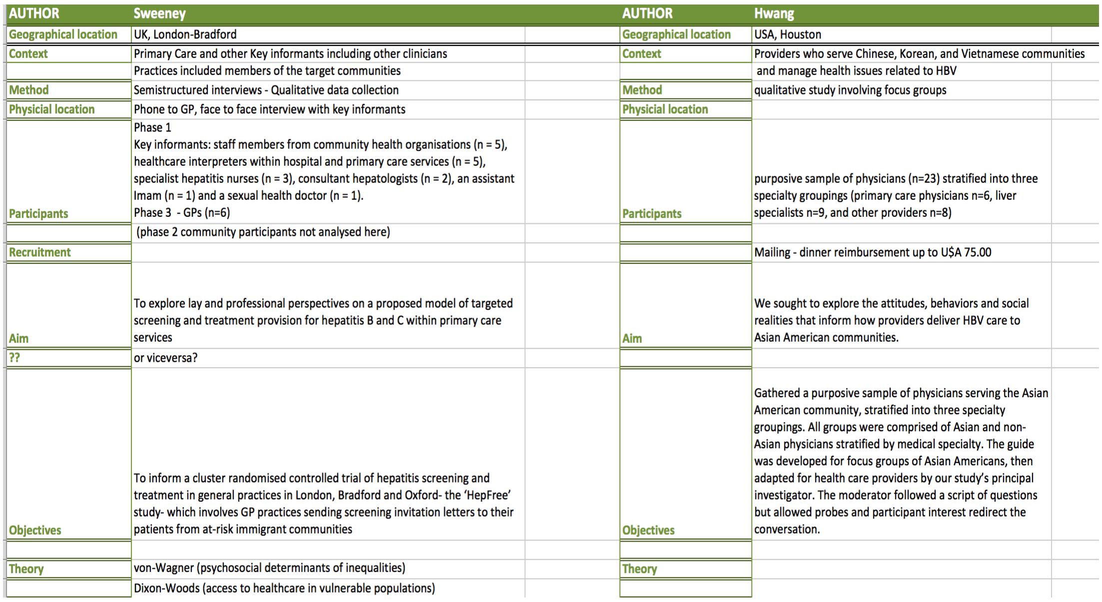
[i] Guirgis, M., Yan, K., Bu, Y. M. & Zekry, a. (2012). General Practitioners' Knowledge and Management of Viral Hepatitis in the Migrant Population. *Internal Medicine Journal*, 42(5), 497–504.

[ii] Robotin, M., Patton & George. (2013). Getting It Right: The Impact of a Continuing Medical Education Program on Hepatitis B Knowledge of Australian Primary Care Providers. *International Journal of General Medicine*, 6, 115.

A2.5 Examples of analysis process

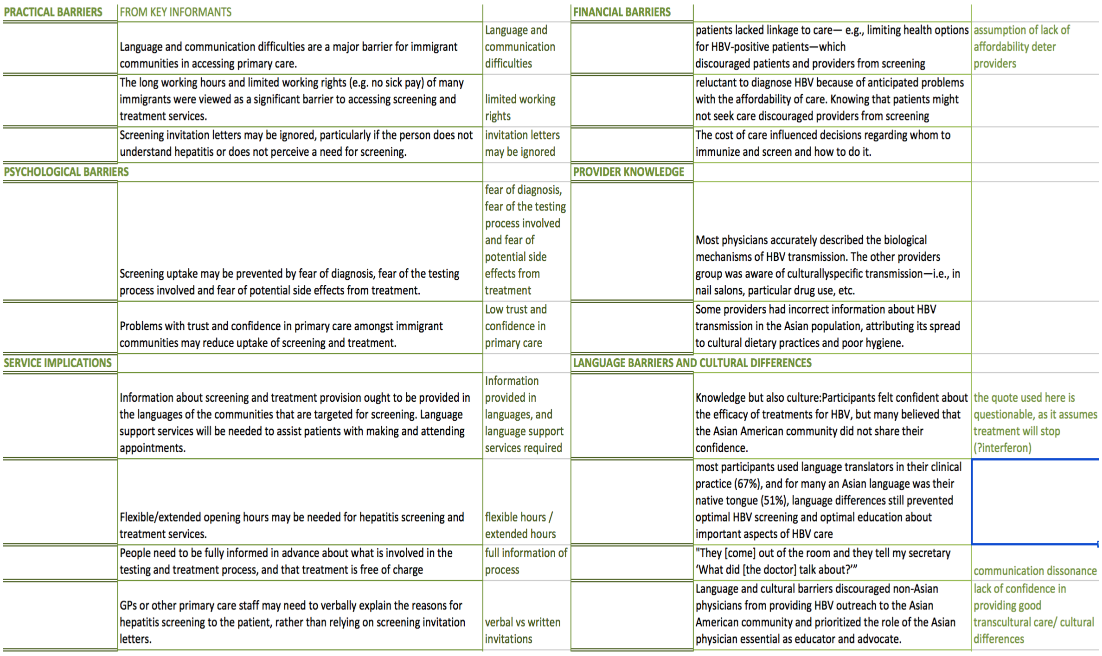
Qualitative studies

Descriptive context analysis



AUTHOR	Sweeney	AUTHOR	Hwang
Geographical location	UK, London-Bradford	Geographical location	USA, Houston
Context	Primary Care and other Key informants including other clinicians	Context	Providers who serve Chinese, Korean, and Vietnamese communities
	Practices included members of the target communities		and manage health issues related to HBV
Method	Semistructured interviews - Qualitative data collection	Method	qualitative study involving focus groups
Physicial location	Phone to GP, face to face interview with key informants	Physicial location	
Participants	Phase 1 Key informants: staff members from community health organisations (n = 5), healthcare interpreters within hospital and primary care services (n = 5), specialist hepatitis nurses (n = 3), consultant hepatologists (n = 2), an assistant Imam (n = 1) and a sexual health doctor (n = 1). Phase 3 - GPs (n=6)	Participants	purposive sample of physicians (n=23) stratified into three specialty groupings (primary care physicians n=6, liver specialists n=9, and other providers n=8)
	(phase 2 community participants not analysed here)		
Recruitment			Mailing - dinner reimbursement up to U$A 75.00
Aim	To explore lay and professional perspectives on a proposed model of targeted screening and treatment provision for hepatitis B and C within primary care services	Aim	We sought to explore the attitudes, behaviors and social realities that inform how providers deliver HBV care to Asian American communities.
??	or viceversa?		
Objectives	To inform a cluster randomised controlled trial of hepatitis screening and treatment in general practices in London, Bradford and Oxford- the 'HepFree' study- which involves GP practices sending screening invitation letters to their patients from at-risk immigrant communities	Objectives	Gathered a purposive sample of physicians serving the Asian American community, stratified into three specialty groupings. All groups were comprised of Asian and non-Asian physicians stratified by medical specialty. The guide was developed for focus groups of Asian Americans, then adapted for health care providers by our study's principal investigator. The moderator followed a script of questions but allowed probes and participant interest redirect the conversation.
Theory	von-Wagner (psychosocial determinants of inequalities)	Theory	
	Dixon-Woods (access to healthcare in vulnerable populations)		

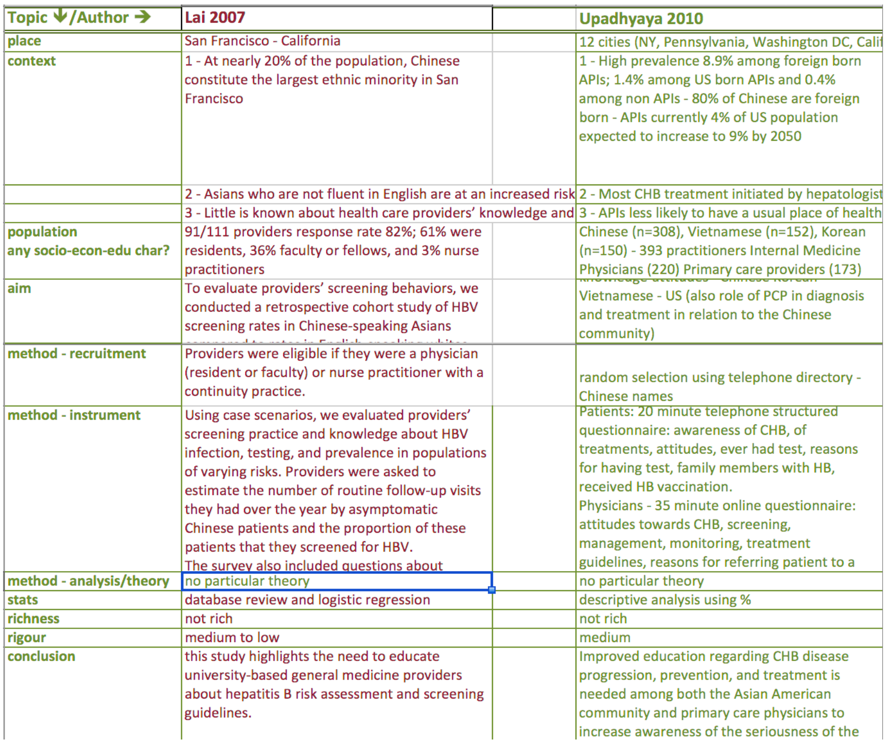
Initial content conceptual analysis



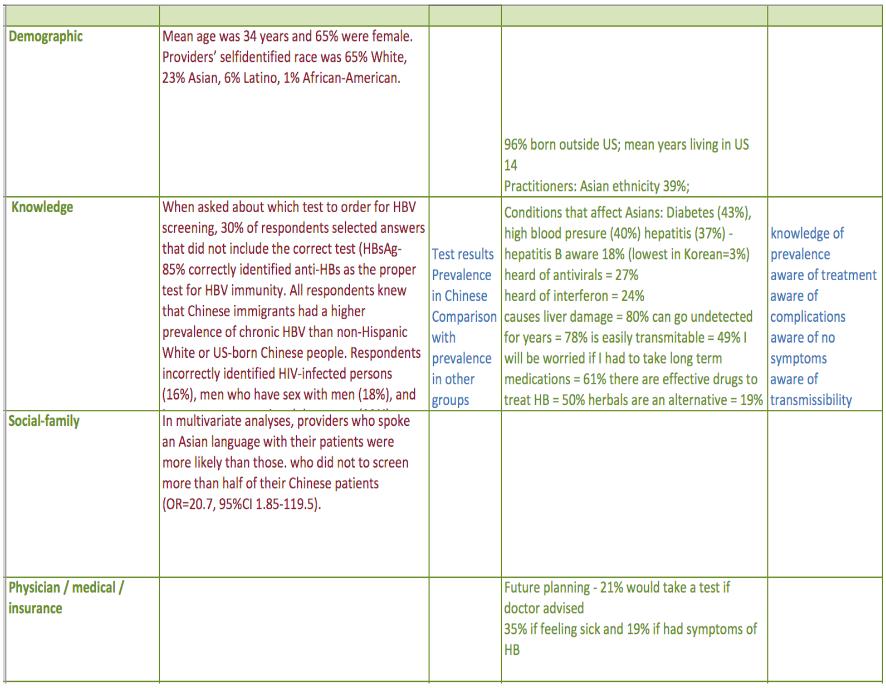
PRACTICAL BARRIERS	FROM KEY INFORMANTS		FINANCIAL BARRIERS		
	Language and communication difficulties are a major barrier for immigrant communities in accessing primary care.	Language and communication difficulties		patients lacked linkage to care— e.g., limiting health options for HBV-positive patients—which discouraged patients and providers from screening	assumption of lack of affordability deter providers
	The long working hours and limited working rights (e.g. no sick pay) of many immigrants were viewed as a significant barrier to accessing screening and treatment services.	limited working rights		reluctant to diagnose HBV because of anticipated problems with the affordability of care. Knowing that patients might not seek care discouraged providers from screening	
	Screening invitation letters may be ignored, particularly if the person does not understand hepatitis or does not perceive a need for screening.	invitation letters may be ignored		The cost of care influenced decisions regarding whom to immunize and screen and how to do it.	
PSYCHOLOGICAL BARRIERS			PROVIDER KNOWLEDGE		
	Screening uptake may be prevented by fear of diagnosis, fear of the testing process involved and fear of potential side effects from treatment.	fear of diagnosis, fear of the testing process involved and fear of potential side effects from treatment		Most physicians accurately described the biological mechanisms of HBV transmission. The other providers group was aware of culturallyspecific transmission—i.e., in nail salons, particular drug use, etc.	
	Problems with trust and confidence in primary care amongst immigrant communities may reduce uptake of screening and treatment.	Low trust and confidence in primary care		Some providers had incorrect information about HBV transmission in the Asian population, attributing its spread to cultural dietary practices and poor hygiene.	
SERVICE IMPLICATIONS			LANGUAGE BARRIERS AND CULTURAL DIFFERENCES		
	Information about screening and treatment provision ought to be provided in the languages of the communities that are targeted for screening. Language support services will be needed to assist patients with making and attending appointments.	Information provided in languages, and language support services required		Knowledge but also culture:Participants felt confident about the efficacy of treatments for HBV, but many believed that the Asian American community did not share their confidence.	the quote used here is questionable, as it assumes treatment will stop (?interferon)
	Flexible/extended opening hours may be needed for hepatitis screening and treatment services.	flexible hours / extended hours		most participants used language translators in their clinical practice (67%), and for many an Asian language was their native tongue (51%), language differences still prevented optimal HBV screening and optimal education about important aspects of HBV care	
	People need to be fully informed in advance about what is involved in the testing and treatment process, and that treatment is free of charge	full information of process		"They [come] out of the room and they tell my secretary 'What did [the doctor] talk about?'"	communication dissonance
	GPs or other primary care staff may need to verbally explain the reasons for hepatitis screening to the patient, rather than relying on screening invitation letters.	verbal vs written invitations		Language and cultural barriers discouraged non-Asian physicians from providing HBV outreach to the Asian American community and prioritized the role of the Asian physician essential as educator and advocate.	lack of confidence in providing good transcultural care/ cultural differences

Quantitative studies

Descriptive and content analysis



Topic ↓/Author →	Lai 2007		Upadhyaya 2010
place	San Francisco - California		12 cities (NY, Pennsylvania, Washington DC, Calif
context	1 - At nearly 20% of the population, Chinese constitute the largest ethnic minority in San Francisco		1 - High prevalence 8.9% among foreign born APIs; 1.4% among US born APIs and 0.4% among non APIs - 80% of Chinese are foreign born - APIs currently 4% of US population expected to increase to 9% by 2050
	2 - Asians who are not fluent in English are at an increased risk		2 - Most CHB treatment initiated by hepatologist
	3 - Little is known about health care providers' knowledge and		3 - APIs less likely to have a usual place of health
population any socio-econ-edu char?	91/111 providers response rate 82%; 61% were residents, 36% faculty or fellows, and 3% nurse practitioners		Chinese (n=308), Vietnamese (n=152), Korean (n=150) - 393 practitioners Internal Medicine Physicians (220) Primary care providers (173)
aim	To evaluate providers' screening behaviors, we conducted a retrospective cohort study of HBV screening rates in Chinese-speaking Asians		Vietnamese - US (also role of PCP in diagnosis and treatment in relation to the Chinese community)
method - recruitment	Providers were eligible if they were a physician (resident or faculty) or nurse practitioner with a continuity practice.		random selection using telephone directory - Chinese names
method - instrument	Using case scenarios, we evaluated providers' screening practice and knowledge about HBV infection, testing, and prevalence in populations of varying risks. Providers were asked to estimate the number of routine follow-up visits they had over the year by asymptomatic Chinese patients and the proportion of these patients that they screened for HBV. The survey also included questions about		Patients: 20 minute telephone structured questionnaire: awareness of CHB, of treatments, attitudes, ever had test, reasons for having test, family members with HB, received HB vaccination. Physicians - 35 minute online questionnaire: attitudes towards CHB, screening, management, monitoring, treatment guidelines, reasons for referring patient to a
method - analysis/theory	no particular theory		no particular theory
stats	database review and logistic regression		descriptive analysis using %
richness	not rich		not rich
rigour	medium to low		medium
conclusion	this study highlights the need to educate university-based general medicine providers about hepatitis B risk assessment and screening guidelines.		Improved education regarding CHB disease progression, prevention, and treatment is needed among both the Asian American community and primary care physicians to increase awareness of the seriousness of the



Demographic	Mean age was 34 years and 65% were female. Providers' selfidentified race was 65% White, 23% Asian, 6% Latino, 1% African-American.		96% born outside US; mean years living in US 14 Practitioners: Asian ethnicity 39%;	
Knowledge	When asked about which test to order for HBV screening, 30% of respondents selected answers that did not include the correct test (HBsAg-85% correctly identified anti-HBs as the proper test for HBV immunity. All respondents knew that Chinese immigrants had a higher prevalence of chronic HBV than non-Hispanic White or US-born Chinese people. Respondents incorrectly identified HIV-infected persons (16%), men who have sex with men (18%), and	Test results Prevalence in Chinese Comparison with prevalence in other groups	Conditions that affect Asians: Diabetes (43%), high blood presure (40%) hepatitis (37%) - hepatitis B aware 18% (lowest in Korean=3%) heard of antivirals = 27% heard of interferon = 24% causes liver damage = 80% can go undetected for years = 78% is easily transmitable = 49% I will be worried if I had to take long term medications = 61% there are effective drugs to treat HB = 50% herbals are an alternative = 19%	knowledge of prevalence aware of treatment aware of complications aware of no symptoms aware of transmissibility
Social-family	In multivariate analyses, providers who spoke an Asian language with their patients were more likely than those. who did not to screen more than half of their Chinese patients (OR=20.7, 95%CI 1.85-119.5).			
Physician / medical / insurance			Future planning - 21% would take a test if doctor advised 35% if feeling sick and 19% if had symptoms of HB	

APPENDIX 3 **Practitioner study topic guide**

A3.1 Topic guide for individual interviews

- 1 - Process involved in identifying hepatitis B in well patients
  - 1.1 - context: clinic, type of patient, resources
  - 1.2 - acknowledgment of risk
  - 1.3 - offering test: acceptance, resistance
- 2 - Factors acting as barriers or facilitators
  - 2.1 - situational factors
  - 2.2 - cultural (professional) factors
  - 2.3 - interaction practitioner/patient
    - 2.3.1 - communication (wider)
      - 2.3.1.a - understanding concepts
      - 2.3.1.b - language and use of interpreters
      - 2.3.1.c - communicating plans
    - 2.3.2 - patient health behavior [differences, understanding]
    - 2.3.3 - practitioner self-efficacy / experience / training

A3.2 Interview guide with questions

SAMPLE INTRODUCTION:

The information document explains this study aims to explore the issues of access to testing and healthcare services by Chinese people affected by hepatitis B. I am interested in your experience in this area as a front line worker/ key position.

The interview will last approximately 30 to 45 minutes; if any questions make you uncomfortable you don’t need to answer them and you are free to discontinue the interview at any point without giving a reason.

1. ROLE:

Can you tell me what are your roles and what do they involve?

Can you describe a typical day in your job? *

How does it differ from colleagues in similar roles?

Can you describe the responsibilities that each role involves? (i.e. clinical, educational, managerial, commissioning)

2. PATIENTS/INTERACTION/COMMUNICATION:

What type of patients do you see? (Ethnicities, age groups)*

Do you see any Chinese patients?

Are there any particular differences in the interaction with Chinese compared to other patients?

Are there any issues with communication, directly or through interpreters? Can you give examples?

Can you remember a recent patient you have seen, can you describe the interaction?

3. HEPATITIS B

What makes you think there is a risk for hepatitis B?

Which particular groups you test regularly for hepatitis B, if any?

How do you explain hepatitis B to a patient?

What would be your response if a patient requests a test (for hepatitis B or other)? Can you explain why?

4. SUPPORT

What support is there to help you carry out your responsibilities?

Which resources do you have / use?

Can you think of any other support you may find useful?

5. BARRIERS TO INNOVATION / DEVELOPMENT:

Are there any special provisions / innovation in your service?

Can you tell me if you had experience in addressing service needs?

How do you go about developing a service / new protocol / other?

What do you think are ways to go about developing a service / new protocol / other?

6. EXTRA QUESTIONS**

What is good/do you enjoy about your job and what do you do well?

Is there anything else you think may be useful to know?

Can you think of anything else that can act as barriers for patients (Chinese or other) to access hepatitis B testing or healthcare?

*Icebreaker questions, soft introductions

** Concluding questions / prompts for ideas that may surface at the end

A3.3 Demographic groups guide and form

Age:	<35	35-49	50-64	>64	
Gender:	F	M	Other		
Ethnic group:	White/ White British	Black/ Black British	Asian/ Asian British/Chinese Asian/ Asian British/other		
Experience current role (y)	<1	1-5	6-10	>10	
Previous experience on relevant role	Y/N				
Professional role	Acute Doctor/Nurse	Specialised Doctor/Nurse	GP/Practice Nurse	Midwife	Other (specify)
Place of work (institutional)	Community	Hospital	Primary care	Other	
City or town of work	Free text				

Date_______________

Participant number____

CATH-B STUDY – PARTICIPANT AND SERVICE CHARACTERISTICS - Practitioners

Role *(please tick one or write if selecting Other)*	Acute medicine doctor Acute medicine nurse General Practitioner Health advisor Midwife Nurse practitioner Specialist/Consultant nurse Specialist/Consultant physician Specialist/Consultant surgeon Other ____________________	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Area – specialty	*Community* *Hospital* *Primary care* *Please describe specialty (if applicable)*	☐ ☐ ☐ ☐
Time in role	Less than 1 year 1 to 5 years 6 to 10 years More than 10 years	☐ ☐ ☐ ☐
Experience (if short)	Previous experience in related role No previous experience in related role	☐ ☐
Gender	M F Other	☐ ☐ ☐
Age group	Up to 34 35 to 49 50 to 64 64 or over	☐ ☐ ☐ ☐
City		
Region		

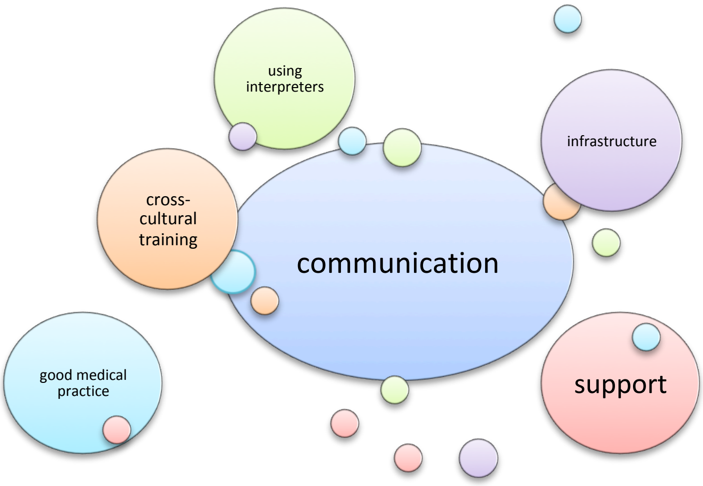
APPENDIX 4 **Analysis: linking themes**

A4.1 Deriving concepts

Example: attitudes towards patients of Chinese ethnicity, mechanisms involved and overarching themes.

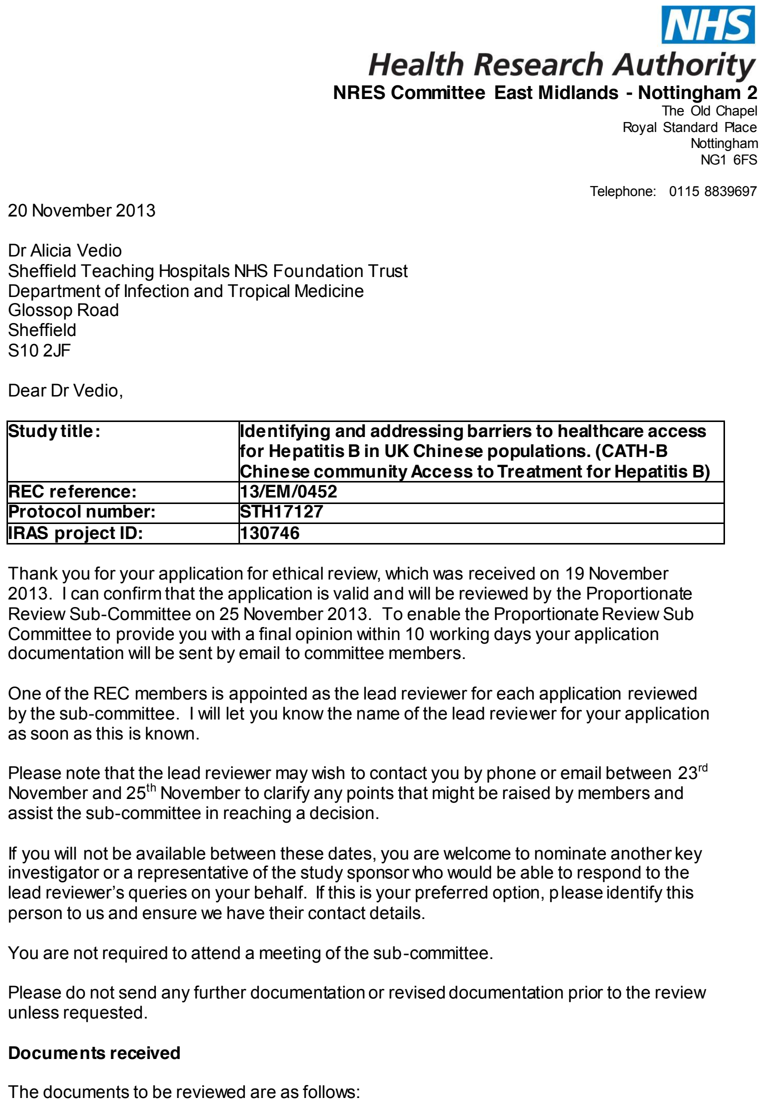
Descriptive theme – Attitudes towards patients	Interpretive themes – Key concepts	Organising themes
Polite, self reliant individuals	Assumptions	Practitioners’ competencies
Reserved	Cross-cultural care awareness	Communication skills
Hard to obtain information from	Self awareness	Individual values

A4.2 Relation between themes



APPENDIX 5 **Ethical approval documents**

A5.1 Ethical approval letters



NHS
Health Research Authority
NRES Committee East Midlands - Nottingham 2
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839697

20 November 2013

Dr Alicia Vedio
Sheffield Teaching Hospitals NHS Foundation Trust
Department of Infection and Tropical Medicine
Glossop Road
Sheffield
S10 2JF

Dear Dr Vedio,

Study title:	**Identifying and addressing barriers to healthcare access for Hepatitis B in UK Chinese populations. (CATH-B Chinese community Access to Treatment for Hepatitis B)**
REC reference:	**13/EM/0452**
Protocol number:	**STH17127**
IRAS project ID:	**130746**

Thank you for your application for ethical review, which was received on 19 November 2013. I can confirm that the application is valid and will be reviewed by the Proportionate Review Sub-Committee on 25 November 2013. To enable the Proportionate Review Sub Committee to provide you with a final opinion within 10 working days your application documentation will be sent by email to committee members.

One of the REC members is appointed as the lead reviewer for each application reviewed by the sub-committee. I will let you know the name of the lead reviewer for your application as soon as this is known.

Please note that the lead reviewer may wish to contact you by phone or email between 23rd November and 25th November to clarify any points that might be raised by members and assist the sub-committee in reaching a decision.

If you will not be available between these dates, you are welcome to nominate another key investigator or a representative of the study sponsor who would be able to respond to the lead reviewer's queries on your behalf. If this is your preferred option, please identify this person to us and ensure we have their contact details.

You are not required to attend a meeting of the sub-committee.

Please do not send any further documentation or revised documentation prior to the review unless requested.

Documents received

The documents to be reviewed are as follows:

Document	*Version*	*Date*
Advertisement	1.0 (Email text staff)	14 November 2013
Investigator CV	(A Vedio)	01 October 2013
Letter of invitation to participant	1.0	14 November 2013
Participant Consent Form: Patient	1.2	14 November 2013
Participant Consent Form: Community	1.2	14 November 2013
Participant Consent Form: Health Professionals	1.3	14 November 2013
Participant Information Sheet: Community	1.2	24 October 2013
Participant Information Sheet: Practitioners	1.2	15 October 2013
Protocol	1.3	01 November 2013
REC application		19 November 2013
Letter from Sponsor		20 November 2013

No changes may be made to the application before the meeting. If you envisage that changes might be required, you are advised to withdraw the application and re-submit it.

Notification of the sub-committee's decision

We aim to notify the outcome of the sub-committee review to you in writing within 10 working days from the date of receipt of a valid application.

If the sub-committee is unable to give an opinion because the application raises material ethical issues requiring further discussion at a full meeting of a Research Ethics Committee, your application will be referred for review to the next available meeting. We will contact you to explain the arrangements for further review and check they are convenient for you. You will be notified of the final decision within 60 days of the date on which we originally received your application. If the first available meeting date offered to you is not suitable, you may request review by another REC. In this case the 60 day clock would be stopped and restarted from the closing date for applications submitted to that REC.

R&D approval

All researchers and local research collaborators who intend to participate in this study at sites in the National Health Service (NHS) or Health and Social Care (HSC) in Northern Ireland should apply to the R&D office for the relevant care organisation. A copy of the Site-Specific Information (SSI) Form should be included with the application for R&D approval. You should advise researchers and local collaborators accordingly.

The R&D approval process may take place at the same time as the ethical review. Final R&D approval will not be confirmed until after a favourable ethical opinion has been given by this Committee.

For guidance on applying for R&D approval, please contact the NHS R&D office at the lead site in the first instance. Further guidance resources for planning, setting up and conducting research in the NHS are listed at http://www.rdforum.nhs.uk. There is no requirement for separate Site-Specific Assessment as part of the ethical review of this research. The SSI Form should not be submitted to local RECs.

Communication with other bodies

All correspondence from the REC about the application will be copied to the research sponsor and to the R&D office for Sheffield Teaching Hospitals NHS Foundation Trust. It will be your responsibility to ensure that other investigators, research collaborators and NHS care organisation(s) involved in the study are kept informed of the progress of the review, as necessary.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

13/EM/0452	**Please quote this number on all correspondence**

Yours sincerely,

Rachel Nelson
REC Assistant

Email: NRESCommittee.EastMidlands-Nottingham2@nhs.net

Copy to: *Ms Sarah Moll*

NHS
Health Research Authority
NRES Committee East Midlands - Nottingham 2
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839309

05 March 2014

Dr Alicia Vedio
Specialty Physician Infection and Tropical Medicine
Sheffield Teaching Hospitals NHS Foundation Trust
Department of Infection and Tropical Medicine
Glossop Road
Sheffield
S10 2JF

Dear Dr Alicia Vedio,

Study title: **Identifying and addressing barriers to healthcare access for Hepatitis B in UK Chinese populations. (CATH-B Chinese community Access to Treatment for Hepatitis B)**
REC reference: **13/EM/0452**
Protocol number: **STH17127**
IRAS project ID: **130746**

Thank you for your email of 17 February 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 26 November 2013

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Advertisement	1.0	13 January 2014
Letter of invitation to participant	11	17 December 2013
Participant Consent Form: Community	1.4	17 December 2013
Participant Consent Form: Healthcare professionals	1.4	27 November 2013
Participant Consent Form: Patient	1.4	17 December 2013
Participant Information Sheet: Patients	1.4	17 December 2013

Participant Information Sheet: Community	1.4	17 December 2013	
Participant Information Sheet: Healthcare professionals	1.4	17 December 2013	

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*	
Advertisement	1.0 (Email text staff)	14 November 2013	
Advertisement	1.0	13 January 2014	
Investigator CV	(A Vedio)	01 October 2013	
Letter from Sponsor		20 November 2013	
Letter of invitation to participant	1.0	14 November 2013	
Letter of invitation to participant	11	17 December 2013	
Participant Consent Form: Community	1.4	17 December 2013	
Participant Consent Form: Healthcare professionals	1.4	27 November 2013	
Participant Consent Form: Patient	1.4	17 December 2013	
Participant Information Sheet: Patients	1.4	17 December 2013	
Participant Information Sheet: Community	1.4	17 December 2013	
Participant Information Sheet: Healthcare professionals	1.4	17 December 2013	
Protocol	1.3	01 November 2013	
REC application		19 November 2013	

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/EM/0452 Please quote this number on all correspondence

Yours sincerely

J. Parfrement

Miss Jessica Parfrement

REC Manager

E-mail: NRESCommittee.EastMidlands-Nottingham2@nhs.net

Copy to: Sponsor/R&D Contact - Ms Sarah Moll

A5.2 Information Sheet

The
University
Of
Sheffield.

School Of
Health
And
Related
Research.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Chinese community access to treatment for Hepatitis B Study (CATH-B)

Participant Information Sheet for health professionals

Invitation

I would like to invite you to take part in a research study on Hepatitis B in the Chinese community in South Yorkshire. Before you decide to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you.

What is the study's purpose?

Hepatitis B is a viral infection which may lead to liver cirrhosis, liver failure and liver cancer. It is more common in certain population groups in the UK such as those of Chinese ethnicity. This research study is looking into the factors that affect how the Chinese community access health services for Hepatitis B. It is our hope that the findings from the study may help improve services for hepatitis B for this community in the UK.

Why have you been chosen?

We would like to speak to members of the public from the Chinese community as well as health professionals, managers and policymakers involved with Hepatitis B services. You have been chosen as you may have particular knowledge and/or experience with this issue.

What will happen to you if you choose to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to confirm your consent verbally and we will arrange an interview. This may be in person or by telephone at a time and place that is convenient for you. The interview will take approximately 20 to 30 minutes, occasionally longer. The interview will be digitally taped for transcription afterwards. These recordings will be anonymised, encrypted and carefully stored. The recordings will be destroyed within 18 months of the end of the study.

What do you have to do?

You will be asked questions on the topic relevant to Hepatitis B in the Chinese community. You only have to respond to questions that you feel comfortable answering.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks to taking part in this study.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will help academics and professionals identify where the knowledge gaps are in this field and address it appropriately.

What happens if the research study stops earlier than expected?

If this is the case the reason(s) will be explained to you.

If you would like to know more about the research please contact:

Name	Department	Telephone number	Email address
Dr A Vedio	Infection and Tropical Medicine, Royal Hallamshire Hospital, S10 2JF	0114 2713562	alicia.vedio@sheffield.ac.uk
Dr A Lee	Section of Public Health, ScHARR Regent Court, 30 Regent Street, Sheffield S1 4DA	0114 2220872	andrew.lee@sheffield.ac.uk

If you have any concerns about the research and would like independent advice please contact:

Name	Department	Telephone number	Email address
Dr. David Fletcher	Registrar and Secretary' of the University of Sheffield Registrar and Secretary's Office, Firth Court, Western Bank, Sheffield, S10 2TN	0114 222 1100	D.E.Fletcher@sheffield.ac.uk
Professor S Heller	Clinical Research Office 11 Broomfield Road S10 2SE	0114 2265934	s.heller@sheffield.ac.uk

Will your taking part in this project be kept confidential?
All the information that I collect about you during the course of the research will be kept strictly confidential. You will not be identified in any reports or publications. Electronic data will be kept secure using password-protected devices. The transcription of the interviews will be anonymous and parts in which participants might be identified will not be used in publications. Data from the study will be stored securely following the study for 5 years and destroyed as confidential waste thereafter.

What will happen to the results of the research project?
This research will take place over 2 years, after which the results will be reported to the Policy Research Programme at the Department of Health who are funding this study. The information will also be presented at academic conferences and be published in research journals. Workshops for dissemination of the findings and improvements derived from the research will be organised in the community and all participants will be invited. You can also obtain a copy of the published report once this is completed by contacting Dr Lee or Dr Vedio on the address or numbers above. The data collected during the course of the project might be used for additional or subsequent research and to inform policy on the provision of testing and of hepatitis B services. Should this be the case, any information about you will continue to be kept confidential.

Who is organising and funding the research?
This research study is funded by the Policy Research Programme of the Department of Health (England). The research will be conducted by a team of researchers from Sheffield Teaching Hospitals NHS Foundation Trust and the University of Sheffield School of Health and Related Research (ScHARR).

Who has ethically reviewed the project?
This project has been reviewed by the Department of Health and ethically approved by National Research Ethics Service Committee East Midlands- Nottingham.

This information sheet is for you to keep. Thank you for your time and help.

A5.3 Consent form

University of Sheffield
Sheffield Teaching Hospitals NHS Foundation Trust

Participant Consent Form (Health Professionals)

Title of Research: **Chinese community access to healthcare for Hepatitis B study**
Name of Researcher: DR ANDREW LEE and Dr ALICIA VEDIO

Participant Identification Number: Please initial box

I confirm that I have read and understood the information sheet version 1.4 dated 17.12.13 explaining the research project and I have had the opportunity to ask questions about the project.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. In addition, should I not wish to answer any questions, I am free to decline.	☐
I understand that my responses will be anonymised. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report(s) that result from the research.	☐
I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities where it is relevant to this research.	☐
I understand that the interviews will be digitally audio-taped and recording securely stored.	☐
I agree for the data collected from me to be used in future related research	☐
I agree to take part in the above research project.	☐

________________________	______________	________________
Name of Participant	Date	Signature (if present)
________________________	______________	________________
Dr Alicia Vedio	Date	Signature

To be signed and dated in presence of the participant
To be signed and dated by researcher with agreement with the professional if verbal consent (phone interview) and signed by professional if present (face to face interview)
Copies:
The participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided for the participants. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

CATH B Consent form v1.4 27 11 13 Health Professionals

APPENDIX 6 **Publications and presentations**

A6.1 Publications

Alicia Vedio, Eva ZH Liu, Andrew CK Lee, Sarah Salway

Improving access to health care for chronic hepatitis B among migrant Chinese populations: A systematic mixed methods review of barriers and enablers.

Journal of Viral Hepatitis 2017;00:1–15. DOI: 10.1111/jvh.12673

Abstract: Migrant Chinese populations in Western countries have a high prevalence of chronic hepatitis B but often experience poor access to health care and late diagnosis. This systematic review aimed to identify obstacles and supports to timely and appropriate health service use among these populations. Systematic searches resulted in 48 relevant studies published between 1996 and 2015. Models of healthcare access that highlight the interplay of patient, provider and health system factors informed data extraction and synthesis. There was strong consistent evidence of low levels of knowledge among patients and community members; but interventions that were primarily focused on increasing knowledge had only modest positive effects on testing and/or vaccination. There was strong consistent evidence that Chinese migrants tend to misunderstand the need for health care for hepatitis B and have low satisfaction with services. Stigma was

consistently associated with hepatitis B, and there was weak but consistent evidence of stigma acting as a barrier to care. However, available evidence on the effects of providing culturally appropriate services for hepatitis B on increasing uptake is limited. There was strong consistent evidence that health professionals miss opportunities for testing and vaccination. Practitioner education interventions may be important, but evidence of effectiveness is limited. A simple prompt in patient records for primary care physicians improved the uptake of testing, and a dedicated service increased targeted vaccination coverage for newborns. Further development and more rigorous evaluation of more holistic approaches that address patient, provider and system obstacles are needed.

Andrew CK Lee, Alicia Vedio, Eva Zhi Hong Liu, Jason Horsley, Amrita Jesurasa and Sarah Salway

Determinants of uptake of hepatitis B testing and healthcare access by migrant Chinese in the England: a qualitative study

BMC Public Health (2017) 17:747 DOI 10.1186/s12889-017-4796-4

Abstract

Background: Global migration from hepatitis B endemic countries poses a significant public health challenge in receiving low-prevalence countries. In the UK, Chinese migrants are a high-risk group for hepatitis B. However, they are an underserved population that infrequently accesses healthcare. This study sought to increase understanding of the determinants of hepatitis B testing and healthcare access among migrants of Chinese ethnicity living in England.

Methods: We sought to obtain and integrate insights from different key stakeholders in the system. We conducted six focus group discussions and 20 in-depth interviews with community members and patients identifying themselves as ‘Chinese’, and interviewed 21 clinicians and nine health service commissioners. Data were thematically analysed and findings were corroborated through two validation workshops.

Results: Three thematic categories emerged: knowledge and awareness, visibility of the disease, and health service issues. Low disease knowledge and awareness levels among community members contributed to erroneous personal risk perception and suboptimal engagement with services. Limited clinician knowledge led to missed opportunities to test and inaccurate assessments of

infection risks in Chinese patients. There was little social discourse and considerable stigma linked to the disease among some sub-sections of the Chinese population. A lack of visibility of the issue and the population within the health system meant that clinicians or commissioners did not prioritise these health needs. Service accessibility was also affected by the lack of language support. Greater use of community outreach, consultation aids, ‘cultural competency’ training, and locally adapted testing protocols may help.

Conclusions: Hepatitis B among migrants of Chinese ethnicity in England can be characterised as an invisible disease in an invisible population. Multi-modal solutions are needed to tackle barriers within this population and the health system.

A6.2 Conference and seminar presentations

26/06/2018

Making Diversity Interventions Count Annual Conference – University of Bradford: *Addressing barriers to access to health care for migrants: barriers affecting access to healthcare in populations of Chinese ethnicity for Hepatitis B* (25 slides – 25 minutes)

30/05/2017

Postgraduate researcher student conference – School of health and related research: *Identifying factors influencing practitioner role in access to care for hepatitis B in Chinese populations* (18 slides – 10 min)

07/04/2017

CLAHRC Y&H - supported seminar: Migration, ethnicity and health inequalities: *Practitioner's role in access - Use of candidacy model* (5 slides – 3 min)

06/10/2016

Royal College of General Practitioners Annual Conference, Harrogate, category: Quality Improvement. *Identifying barriers to healthcare for chronic hepatitis B in Chinese patients. A qualitative study of Health Practitioners* (Poster)