Enhancing Community Engagement and Support for People Living with Hepatitis B in Greater Manchester

A Community Research Project
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Contents

Executive Summary 3
Key Findings at a glance 4
Introduction and Background 5
Objectives and Methodology 6

Key Findings 9
1. Immigration related healthcare avoidance 10
2. Information gaps at diagnosis 11
3. Contributors to isolation 14
4. Strong demand for peer support 15
5. Stigma and cultural barriers 16
6. Partner support: critical but unsupported 20
7. Clinical care vs system navigation 22

Summary and Recommendations 24
Limitations 29
Bibliography 29
Acronyms and Appendix 30

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Executive Summary

Hepatitis B is a chronic viral infection disproportionately affecting minoritised ethnic communities in Greater Manchester. An estimated 268,767 people were living with chronic hepatitis B in the UK in 2022, with only 43.6% having been diagnosed.[1] Over 95% of chronic infections are among individuals who acquired the virus overseas, highlighting the disproportionate burden within the migrant population.[1] Despite this, hepatitis B receives significantly less support and resources than HIV or hepatitis C, leaving those affected with little guidance at diagnosis, no consistent psychosocial support, no peer structures, and no tailored resources.

Over 400 people previously undiagnosed and living with hepatitis B have been identified through Blood Borne Virus (HIV, hepatitis B and hepatitis C) opt-out testing in hospital Emergency Departments across Greater Manchester since 2024. This programme has brought gaps in diagnosis, support and engagement with care into sharp focus, and provides the context for BHA for Equality to undertake the Hep B Voices project, funded by Gilead Sciences.

This report presents the findings from a mixed-methods study exploring: the lived experience of diagnosis and care; information and knowledge needs; the impact on relationships, isolation and social life; barriers to engaging with services; the role of stigma and cultural beliefs; immigration-related healthcare avoidance; and the demand for peer support. Using a mixed-methods approach, a questionnaire (n=55) and in-depth telephone interviews (n=7), BHA identified substantial barriers: unclear information at diagnosis, limited family-oriented guidance, weak primary-secondary care communication, fear of sharing a diagnosis, and practical issues around travel, language, and immigration-related anxieties.

In response, BHA co-produced the "Living Well with Hepatitis B" Guide, informed by participant voices and cultural contexts, alongside a set of practical recommendations for strengthening post-diagnosis support, improving GP-to-hepatitis team communication, and expanding culturally grounded care. This report underscores the urgent need to bring hepatitis B in line with the infrastructure available for other BBVs, ensuring the benefits of expanded ED testing translate into better long-term outcomes for all communities affected.

> *"Thanks to continued efforts and support, people with hepatitis C and HIV now have better access to treatment, care, and services, which has driven remarkable progress in care and outcomes.*
>
> *In contrast, hepatitis B, despite having similar public health targets, has not received the same level of support. The emergency department testing programme marks a pivotal step in addressing this imbalance.*
>
> *It has already identified more individuals living with hepatitis B than those with HIV and hepatitis C combined. This initiative is saving lives, and I am truly honoured to collaborate with all our partners in this vital work."*
>
> – Dr Javier Vilar,
> Consultant in Infectious
> Diseases at Manchester
> University NHS
> Foundation Trust

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[1] Hepatitis B in England 2024, UK Health Security Agency Hepatitis B in England 2024 - GOV.UK

Key Findings at a glance

The statistics below summarise the most significant findings from the 55-response questionnaire:

90.9% satisfied with clinical care

60% never offered emotional support

69% want peer support

91% have no peer/community support

43.6% received no materials at diagnosis

71% had little/no prior knowledge of Hep B

55% left diagnosis without usable information

Introduction and Background

BHA for Equality is a health and wellbeing focused charity working across Greater Manchester, Liverpool, Leeds, Wakefield, Coventry and Warwickshire to address health inequalities affecting racially minoritised communities.

For more than three decades, BHA has provided culturally informed health promotion, community engagement, disease prevention initiatives, and targeted support for people disproportionately affected by HIV. This project builds on that legacy by focusing specifically on the experiences of people living with hepatitis B, an area where support systems remain significantly underdeveloped compared to other blood -borne viruses (BBVs).

Between January and December 2025, BHA conducted a mixed methods study in partnership with Manchester University Hospitals NHS Foundation Trust (MFT) to better understand the lived experiences, service needs and challenges faced by people from minoritised ethnic communities living with hepatitis B in Greater Manchester. The project combined a digital and paper based questionnaire (n=55) with in depth telephone interviews carried out in participants' preferred languages. Although focus groups were planned, these could not proceed due to work commitments, stigma, and confidentiality concerns, prompting BHA to adapt the approach and use one to one interviews instead.

Since 2024, the Greater Manchester ED testing programme has conducted almost 500,000 BBV tests across 9 local hospitals, identifying over 400 people with hepatitis B, nearly 500 with Hepatitis C, and more than 160 with HIV.[2] This local picture aligns with national findings from the Public Health Evaluation of the blood-borne virus opt-out testing programme, which shows a clear difference in incidence across the 3 blood-borne viruses. Emergency Departments completed 1,981,590 HIV tests and identified 391 new HIV diagnoses, meaning roughly 1 new case was found for every 5000 tests. In comparison, 1,502,799 hepatitis C tests identified 762 new cases, or approximately 1 new case for every 2000 tests. Hepatitis B showed a far higher incidence, with 1,185,678 tests leading to 1,957 new diagnoses, which equates to only around 600 tests needed to identify a single new case.3

HIV and Hepatitis C have long benefited from better care pathways, established community support, peer support networks and strong clinical awareness in Greater Manchester. Greater Manchester Integrated Care Partnership highlights how the HIV response in the region has achieved major public health successes, including a 52% reduction in new HIV diagnoses between 2014 and 2023, 95% of people knowing their status, 99% on treatment, and 97% achieving undetectable viral load.[3]

Hepatitis B does not have equivalent support systems that underpin successful engagement in seeking prevention, testing, treatment and care. This report represents the findings from this study and explores how newly diagnosed hepatitis B patients frequently reported limited information at diagnosis, uncertainty about next steps, weak GP to hospital communication, stigma, and a lack of culturally relevant guidance for themselves and their families.

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[2] Manchester University NHS Foundation Trust, 'Over 1,000 new HIV and hepatitis diagnoses made through Greater Manchester A&E testing', 16 October 2025, available at: https://tinyurl.com/mrs7vn8e

[3] UK Health Security Agency, Public Health Evaluation of BBV Opt-Out Testing in Emergency Departments in England: 24 month interim report, available at: https://tinyurl.com/583sd93w

Objectives and Methodology

Objectives

The Hep B Voices project aimed to deepen the understanding of the hepatitis B care pathway and guide improvements for minoritised ethnic communities living with hepatitis B in Greater Manchester. MFT identified a gap in patient voices within their service design and wished to ensure that people living with hepatitis B had an opportunity to shape future services, information resources, and care provision.

The care pathway refers to the sequence of steps a person with hepatitis B moves through, from diagnosis and initial assessment, through ongoing monitoring, treatment and management, to long-term support, spanning hospital hepatitis services, GP care, and community support.

The project aimed to:

1. **Explore patient experiences:** Gather the lived experiences of ethnic minority patients diagnosed with hepatitis B in Greater Manchester, focusing on how they navigate the pathway from diagnosis to care. Over 95% of people with new chronic hepatitis B infections in the UK are migrants who acquired their infection in their country of birth.[4]
2. **Develop patient-centred resources:** Produce clear, accessible materials to support newly diagnosed individuals and improve their understanding of hepatitis B and the care pathway.
3. **Equip healthcare professionals:** Create culturally informed resources for clinical teams so they can better understand the cultural and linguistic needs of affected communities.
4. **Strengthen culturally appropriate care:** Ensure hospital teams are able to provide respectful, relevant and culturally sensitive information and support to patients at the point of diagnosis and beyond.

Methodology

The research was conducted by BHA for Equality in partnership with Manchester University Hospitals NHS Foundation Trust (MFT) between January and December 2025. The study used a convergent parallel mixed methods approach to ensure both breadth and depth, capturing statistical trends alongside lived experiences and cultural context. Participant eligibility criteria included adults (18+) living with hepatitis B and currently engaged with NHS hepatitis services in Greater Manchester.

Survey

A digital and paper based questionnaire was disseminated across the following hospitals in Greater Manchester: North Manchester General Hospital, Royal Oldham Hospital, Rochdale Infirmary, Manchester Royal Infirmary, Wythenshawe Hospital, Salford Royal Hospital, Royal Bolton Hospital, Wigan Infirmary, and Stepping Hill Hospital. Staff at these sites supported the process by displaying recruitment posters and facilitating participant sign up.

To ensure the study was accessible to non English speaking communities disproportionately affected by hepatitis B, the questionnaire was translated into Mandarin, Cantonese and Urdu. Participants were able to complete the survey either digitally via a QR code or in print, according to their preference.

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[4] UK Health Security Agency, Hepatitis B: migrant health guide. Available at: https://www.gov.uk/guidance/hepatitis-b-migrant-health-guide

A total of 55 responses were received, with most of them coming from North Manchester General Hospital, which holds the largest clinic. The questionnaire collected quantitative and qualitative data on:

- Demographic characteristics (ethnicity, gender, age and country of birth)
- Clarity of information received at diagnosis
- Appointment attendance and any barriers encountered
- Experiences of stigma, judgement or anxiety
- Treatment status and confidence in managing hepatitis B
- Preferred languages and preferred information formats

Interviews

To complement the survey, BHA conducted a series of in-depth telephone interviews (n=7), using participants' preferred languages to ensure accessibility and comfort. The interviews followed a semi-structured guide exploring:

- The emotional and practical experience of receiving a hepatitis B diagnosis
- Understanding of the condition and the care pathway
- Interactions with hospital teams, GPs and hepatitis services
- Impact on relationships, family life, work and mental wellbeing
- Experiences of stigma, immigration related fears and confidentiality concerns
- Suggestions for improving communication, resources, and culturally appropriate care

These interviews were essential for uncovering the contextual and cultural dimensions of care, revealing how factors such as migration history, language, stigma and mistrust shape a patient's journey far beyond what the survey alone could capture.

Focus Groups

Focus groups were originally planned as a core method for capturing group discussions, shared cultural experiences and collective reflections on the hepatitis B pathway. However, despite significant outreach and scheduling flexibility, focus groups were extremely difficult to deliver. Ultimately, only one participant attended the scheduled focus group sessions.

Key challenges that prevented individuals from participating in the focus groups included:

- Stigma and fear of having their status known by others, particularly within tight knit migrant communities
- Concerns about confidentiality, even when anonymity was offered
- Work and shift based employment, which prevented many from attending at set times
- Hesitancy to participate in group settings where others might know or suspect their hepatitis B status

While this outcome highlighted the limitations of group based methods for this population, it was itself an important finding: people living with hepatitis B often do not feel safe or comfortable discussing their condition in new group environments, especially when compared with the more established HIV support ecosystems. For example, groups for people from ethnic minorities living with HIV in Greater Manchester are safe places provided by support organisations like George House Trust, who have spent years building the confidence and trust of these communities.

In response, BHA ethically adapted the methodology by shifting toward individual interviews, which participants reported feeling much safer and more private.

Integration of Findings

After independently analysing survey data and interview narratives, findings were integrated to highlight:

- Areas where data converged, such as inconsistent clarity at diagnosis and the importance of culturally tailored information
- Areas where data diverged, such as confidence in managing hepatitis B, appeared higher in the survey than reported emotionally in interviews
- Areas where one method expanded on the other, for example: interviews revealing immigration fear and experiences of stigma that were not captured in the questionnaire

This integrated analysis provided a richer understanding of the hepatitis B pathway. It has also enabled the development of practical, culturally informed recommendations, and the co-production of the Living Well with Hepatitis B Guide.

Analysis

Using Braun and Clarke's[5] six-phase thematic analysis framework enabled a rigorous and transparent approach to identifying and organising patterns within the data. Through systematic familiarisation, coding, theme development, review, and refinement, the framework supported the integration of insights across both interview and questionnaire data, ensuring that findings were grounded in participants' accounts rather than preconceived assumptions. This structured process enhanced analytic clarity, facilitated comparison across demographic groups and service contexts, and strengthened the credibility and trustworthiness of the findings by making the progression from raw data to final themes explicit and auditable.

Ethical consideration

Ethical considerations were central to the study design and implementation. All participants provided informed consent prior to participation, with clear explanations of the study's purpose, procedures, and their right to withdraw at any time without consequence. Confidentiality was rigorously protected through secure data storage and restricted access, and participants were explicitly reassured that no information would be shared with immigration authorities or other external agencies. All findings were reported in anonymised form to prevent the identification of individuals, ensuring privacy and safeguarding participants throughout the research process.

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[5] Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), pp. 77–101. doi: 10.1191/1478088706qp063oa

Key Findings

The research identified 7 interconnected themes that shape the lived experience of people affected by hepatitis B:

1. Immigration related healthcare avoidance
2. Information gaps at diagnosis
3. Contributors to isolation
4. Strong demand for peer support
5. Stigma and cultural barriers
6. Partner support
7. Clinical care vs system navigation

1. Immigration related healthcare avoidance

Immigration-related healthcare avoidance refers to the pattern where individuals, including those with secure legal status, avoid NHS testing, treatment or participation in health research due to fears that engaging with healthcare may have negative immigration consequences. A significant theme was such avoidance driven by immigration fears. During the research process, BHA encountered a prospective participant ("X") whose experience illustrated this dynamic clearly.

The Case of Participant 'X'

X is a Chinese man who initially agreed to participate in a group discussion, but withdrew after asking for:

- Advance access to interview questions
- Confirmation that no CCTV would be present
- Assurance that NHS staff would not know he was taking part
- Repeated guarantees of confidentiality
- X opted for a telephone instead. Once reassured that the call was not being recorded, he disclosed the following:
- He had read media claims that migrants who do not "contribute" may lose the right to stay in the UK. New contribution-based settlement model to reduce net migration - GOV.UK
- In his community, people believe that having a chronic illness and using NHS services labels them as a burden, putting visas or Indefinite Leave to Remain (ILR) at risk
- He suspects some of his family members have hepatitis B, but they refuse testing due to fear of government visibility
- The family uses herbal teas instead of evidence-based treatment
- Although he has Indefinite Leave to Remain (ILR), he fears policy changes because his country does not allow dual nationality
- He distrusts charities because, in his home country, charities are linked to government surveillance.
- Crucially, he stated these beliefs were common in his social circle.

Public Health Implications: The hidden population challenge

This fear-driven avoidance behaviour has severe consequences:

- Late presentation with cirrhosis or liver cancer
- People remaining invisible to clinics, surveillance systems and elimination strategies
- Reliance on ineffective remedies instead of antivirals
- Undetected transmission within households and amongst close contacts who are not vaccinated

Significance as a Research Finding

While hostile environment policies and immigration fears have been shown to deter migrants from seeking healthcare, this study highlights that hepatitis B-specific avoidance exists even among migrants with ILR. This reveals a distinct and largely unaddressed barrier that complicates any attempt to expand hepatitis B support.

> *"The fear resulting from real or perceived links between healthcare systems and immigration enforcement has been widely documented to deter and reduce access to healthcare among some migrant groups both within the UK and other European countries."*
>
> – Rassa et al. (2023)[6]

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[6] Rassa et al., The impact of NHS charging regulations on healthcare access and utilisation among migrants in England. BMC Public Health, 28 February 2023. Available at: https://link.springer.com/article/10.1186/s12889-023-15230-9

2. Information gaps at diagnosis

Both interviews and questionnaires confirm systematic information failure, both at diagnosis in home countries and in the UK. The moment of diagnosis represents a critical juncture in the hepatitis B journey, a time when information needs are highest, emotions are intense, and the foundation is laid for future engagement with care.

The findings reveal a substantial knowledge deficit regarding hepatitis B among participants before diagnosis. Over two-thirds (71%) of respondents had minimal or no prior knowledge of the condition, with the largest proportion (38%) reporting awareness of the name but lacking substantive understanding, and a further third (33%) having never heard of hepatitis B at all.

Pre-Diagnosis Knowledge

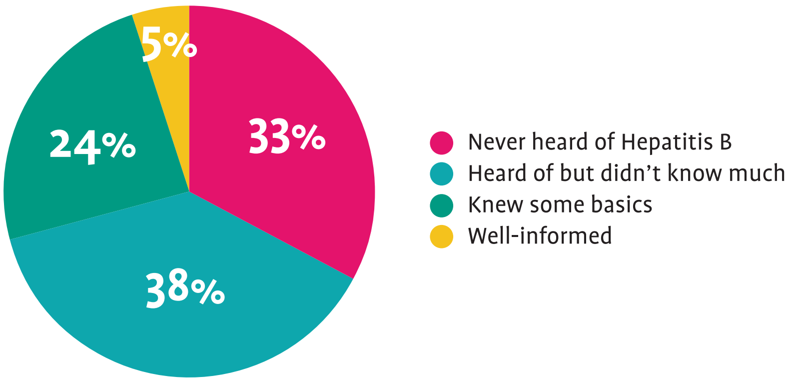

Fig 1. Pre-diagnosis knowledge

Of the 55 respondents, 41 were diagnosed in the UK while the remaining 14 were diagnosed abroad. Of these, only a minority demonstrated adequate knowledge of hepatitis B, with just 24% reporting basic understanding and a mere 5% considering themselves well-informed. This pattern of low health literacy is particularly concerning given that most participants originated from endemic regions where hepatitis B prevalence is high.

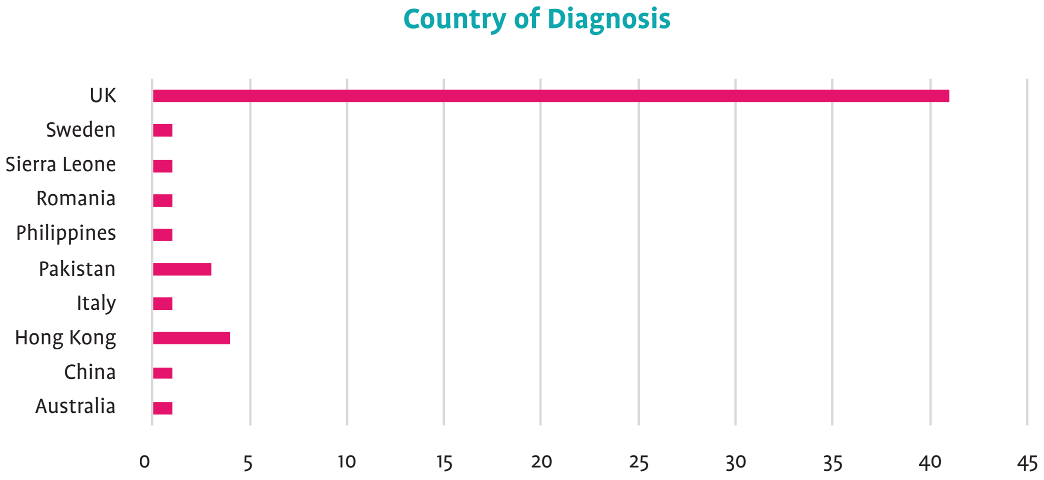

Fig 2. Country of diagnosis

The predominance of superficial awareness without deeper understanding suggests that whilst the term "hepatitis B" may circulate within communities, meaningful information about transmission, symptoms, prevention, and treatment consequences remains largely inaccessible. This knowledge gap has significant implications for both individual health-seeking behaviours and public health strategies, as it indicates that many individuals from at-risk populations may be unaware of their vulnerability or the importance of testing and treatment, potentially contributing to delayed diagnosis and continued transmission within households and communities.

> *"This was my first time learning about it. I was diagnosed at 12 years. Teachers didn't know about it, parents didn't want to talk about it. I thought I was going to die."*
>
> – Interview participant

Information clarity at diagnosis

The data reveal a mixed picture regarding the clarity of information provided at the point of diagnosis. While nearly two-thirds (63%) of participants reported receiving clear or somewhat clear information, a substantial minority experienced communication difficulty. Notably, 46% rated the information as "very clear," suggesting that when communication is effective, it can be highly successful.

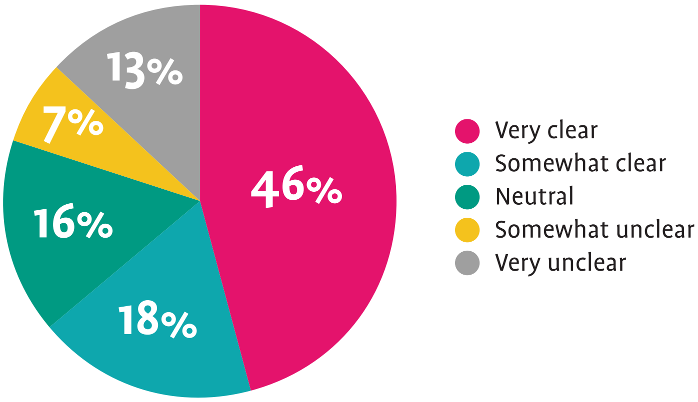

Fig 3. Information clarity at diagnosis

However, one in five respondents (20%) found the information unclear or very unclear, and 13% found it "very unclear." This is especially troubling, as poor initial communication can trigger anxiety, misconceptions, and reduced engagement with follow-up care. This is reflected in the interviews, where some participants described leaving their diagnosis appointment with little meaningful understanding of their condition. One participant recalled being told only to take medication and that hepatitis B causes damage, while another recalled receiving nothing more than a link to a website with no further explanation.

These disparities are particularly concerning given that only three of the 55 respondents were born in the UK. When asked about their preferred language for communication, 54.5% preferred English only, while a further 10.9% preferred English alongside another language such as Urdu, Cantonese or Polish. A quarter of respondents (25.5%) preferred a language other than English entirely, including Chinese, Cantonese, Mandarin, Urdu, Punjabi, Arabic, Bengali and Persian. This reflects the diverse linguistic needs of people living with hepatitis B in Greater Manchester.

What makes this more concerning is that even when information is delivered well, research shows that between 40% and 80% of what a clinician says during a consultation is forgotten almost immediately, and nearly half of what is remembered is recalled incorrectly (Kessels, 2003)[7]. Anxiety at the point of diagnosis makes this worse, as people receiving serious news are unlikely to take in much of what follows. For people newly diagnosed with hepatitis B, this makes written, accessible take-home information a necessity, not an afterthought.

Reading materials received

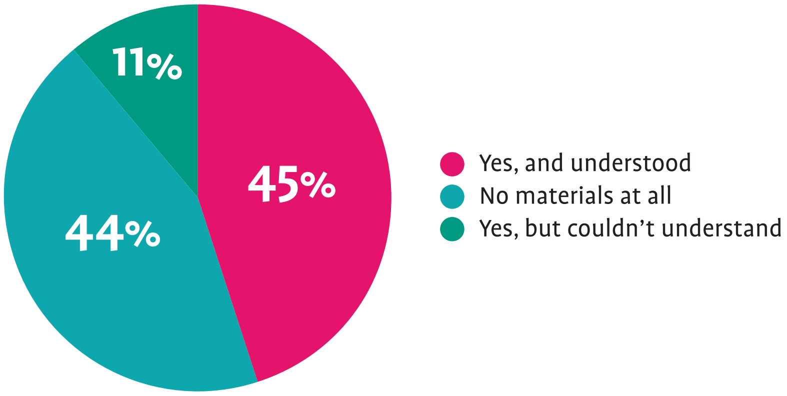

Fig 4. Reading materials received

The provision of written information at diagnosis reveals a critical gap in patient education, with less than half (45%) of participants receiving reading materials they could understand. In addition, 44% reported that they had not received reading materials, representing a significant gap in take-home information to support comprehension and retention of their diagnosis. This is particularly problematic given that verbal information provided during consultations is easily forgotten, especially when delivered under the stress of receiving a diagnosis. An additional 11% reported receiving materials they could not understand, likely reflecting language barriers, low health literacy, or inappropriately technical content. Combined, this means that 55% of participants left their diagnostic consultation without accessible reading information to refer back to.

The lack of culturally and linguistically appropriate materials is especially concerning for migrant populations who may already face communication challenges and have limited pre-existing knowledge about hepatitis B. Without comprehensible written resources, patients are left reliant solely on their recall of a potentially overwhelming verbal consultation, which may contribute to poor understanding of transmission routes, treatment adherence, and the importance of household screening. This gap in information provision likely exacerbates existing health inequalities and undermines efforts to prevent onward transmission within families and communities.

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[7] Kessels, R.P.C. (2003) 'Patients' memory for medical information', *Journal of the Royal Society of Medicine,* 96(5), pp. 219–222. doi:10.1258/jrsm.96.5.219

What Patients Didn’t Know

Across the interviews, common knowledge gaps were identified. Participants did not know:

- How the virus is transmitted (especially sexual transmission)
- Whether sharing food/utensils is safe
- Impact on intimacy and family planning
- Whether the condition is fatal or manageable
- Next steps beyond clinical appointments
- How to protect family members
- If there was a vaccine for hepatitis B

> *“If she hadn’t read about it, it’s on her, but she wasn’t given anything.”*
>
> – Participant describing partner who was also diagnosed with hepatitis B.

3. Contributors to isolation

60% of survey participants responded that they were not offered any emotional support following diagnosis. The rate is even lower for those who participated in the in-depth interviews, with none of them indicating they had received any form of emotional support. A further 90.9% reported having no support groups, friends or health professionals to help them cope with hepatitis B. 85% of the participants from the interview indicated a need for therapy and counselling, yet the system does not provide any. Currently, patients receive a note with suggestions of sites that they could use to read more and to have more support. Suggested sites include Hep B Companion, Hep B Positive and The British Liver Trust. However, these are not Greater Manchester-specific support systems tailored for residents.

> *“Therapy would help... It can be a lonely time. You can’t really talk to your friends.”*
>
> – Interview participant

Loneliness is also a major challenge among younger and older respondents. Because of how challenging it is to talk about one’s status and due to the fear of experiencing stigma, patients find it hard to talk to other people. Patients are often like islands on their own, with no one to talk to who understands their condition, or someone who is like them.

> *“I feel like I’m living a double life. I talk to my friends about other things, but I cannot talk to them about my condition.”*
>
> – Interview participant

4. Strong demand for peer support

> *"Peer support is a valuable resource for people and their families and carers; empowering them to take ownership of, and have more control over, their health and wellbeing. It enables people to develop the knowledge, skills, and confidence to self-manage and address other issues that might be affecting their health, such as loneliness or self-esteem."*
>
> – NHS England, supported self-management: peer support guide[8]

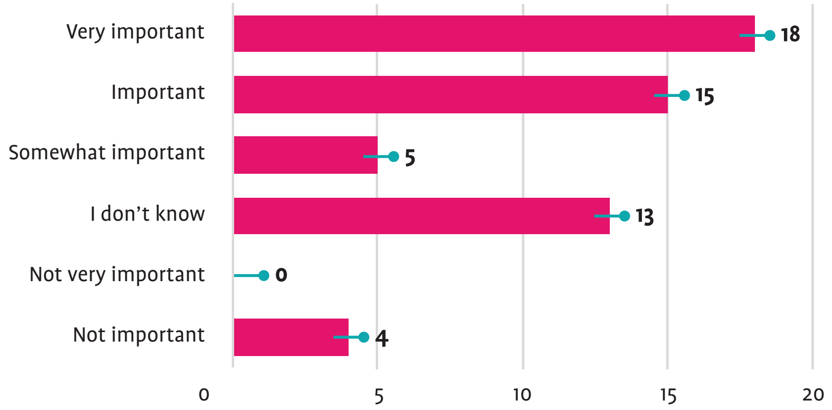

Fig 5. Importance of peer support

Our research found unmet demand for peer support. 69% of respondents in the questionnaire indicated that they found it somewhat important, important or very important to have a peer support system in place. Data from the in-depth interview follows the same convergent trend, with all participants sharing that they would like to have a peer support system in place. Despite this need, there are no hepatitis B-specific peer systems in Greater Manchester to help them navigate their clinical pathway and community.

> *"I would want to get support from people who are living with hep B... I want to talk to other people in the same situation."*
>
> – Interview participant

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[8] NHS England, Supported self-management: peer support guide. Available at: https://www.england.nhs.uk/long-read/peer-support

5. Stigma and cultural barriers

Stigma represents one of the most pervasive yet elusive barriers to help-seeking behaviour. Its influence extends beyond overt discrimination to shape individuals' decisions about whether to talk about their condition, seek care, or engage with support services. Understanding how stigma operates requires examining its measurable manifestations and nuanced structural and psychological dimensions.

Quantitative Findings: Low Reported Discrimination

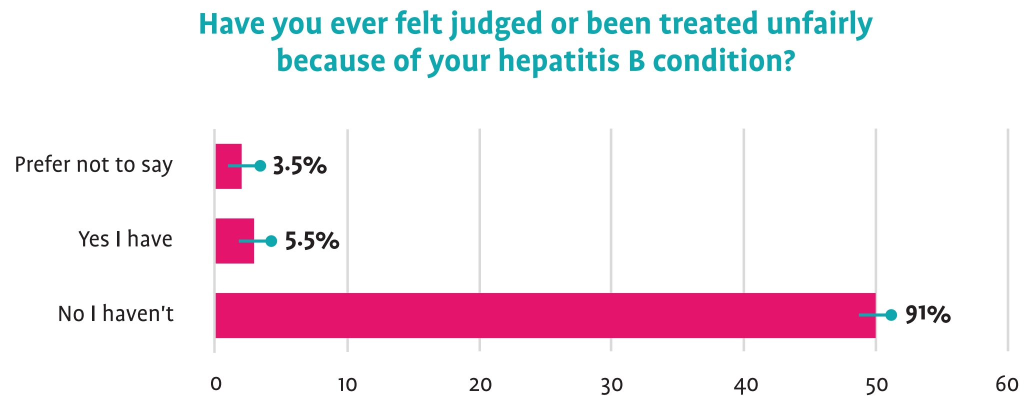

Fig 6. Stigma from quantitative findings

The questionnaire findings revealed a low prevalence of directly experienced stigma. 91% of respondents indicated they had not felt judged or treated unfairly because of their hepatitis B condition, while only 5% reported experiencing discrimination either within their community or when accessing care through the NHS. These figures suggest that, on the surface, most individuals with the condition do not encounter overt prejudice or mistreatment in their daily lives or healthcare interactions. Such findings might initially be interpreted as evidence that stigma poses a minimal barrier to this population. However, closer examination through qualitative methods revealed a more complex picture.

Qualitative Findings: The Hidden Burden of Anticipated Stigma

Interview narratives told a different story. Rather than reporting low levels of stigma, participants described living with a constant awareness of potential judgment that shaped their behaviour in profound ways. This manifested not as accounts of discriminatory encounters, but as fear of what might happen should others discover their condition. Participants spoke of carefully managing information about their health, avoiding conversations that might lead to sharing their diagnosis, and strategically selecting which individuals, if any, could be trusted with their diagnosis. One participant captured this experience:

> *"I haven't told anyone at work. Not because anything has happened, but because I know how people talk about these things. I've heard them. So, I just... don't put myself in that position."*
>
> – Interview participant

The account by participant X exemplifies how anticipated stigma generates protective concealment behaviours. Participants were not reporting low stigma because prejudice was absent from their social environments; rather, they had developed strategies to avoid situations where stigma might be enacted.

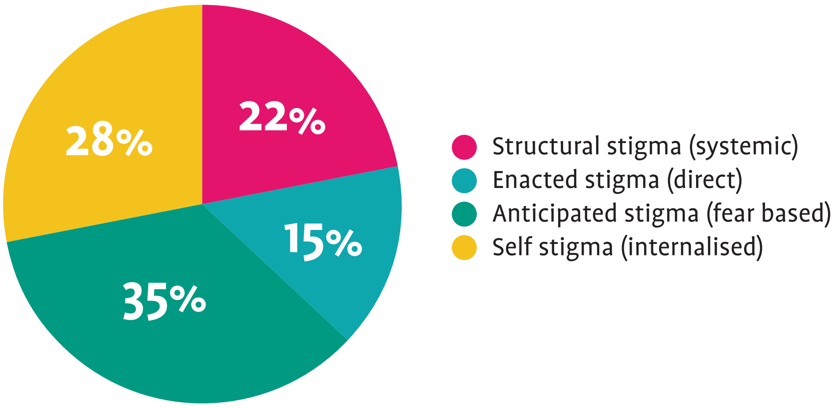

Fig 7. Stigma from qualitative findings

This distinction aligns with Corrigan and Watson's (2002) theoretical differentiation between enacted and anticipated stigma.[9] Enacted stigma refers to direct experiences of discrimination, social exclusion, or prejudicial treatment. Anticipated stigma, by contrast, describes the expectation that such treatment will occur, leading individuals to modify their behaviour proactively. Research consistently demonstrates that anticipated stigma often exceeds enacted stigma in both prevalence and behavioural impact (Clement et al., 2015).[10] Individuals may never experience overt discrimination precisely because their anticipatory behaviours, concealment, selective sharing of their diagnosis, and social withdrawal successfully prevent exposure to potentially stigmatising situations.

[9] Corrigan, P. W. and Watson, A. C., The paradox of self stigma and mental illness, Clinical Psychology: Science and Practice, 9(1), pp. 35–53, 2002.Available at: https://doi.org/10.1093/clipsy.9.1.35

[10] Clement, S., Schauman, et al., What is the impact of mental health related stigma on help seeking? A systematic review of quantitative and qualitative studies, Psychological Medicine, 45(1), pp. 11–27, 2015. Available at: https://doi.org/10.1017/S0033291714000129

Cultural Dimensions of Stigma

Stigma as a Collective Phenomenon

The qualitative findings revealed that stigma operated not merely at the individual level, but as a broader cultural phenomenon embedded within community norms and family structures. Participants described environments where certain health conditions were simply not discussed, not because explicit prohibitions existed, but because collective silence had rendered such topics socially invisible. Within families, unwritten rules governed what could be acknowledged openly versus what must remain hidden to preserve reputation. One participant explained:

> *"In my family, we don't talk about these things. It's not that anyone has said I can't.... It's just understood. You deal with it quietly, privately. You don't burden others or bring shame."*
>
> – Interview participant

This expectation extended to the wider community, where participants perceived that sharing their diagnosis would reflect not only upon themselves but upon their families and social networks. Critically, the nature and expression of stigma varied across cultural communities, shaped by distinct beliefs, misconceptions, and social practices.

South Asian Communities: Misconceptions and Moral Judgement

3 interview participants from South Asian communities described stigma rooted in widespread misinformation. The condition was frequently conflated with "black or yellow jaundice", a culturally familiar but medically imprecise concept carrying negative connotations. Persistent myths about transmission and cure further compounded the problem; one participant recounted hearing that *"Sprite cured someone's hep B,"* reflecting reliance on folk remedies that delayed appropriate medical care.

More damaging was the association between hepatitis B and sexual promiscuity, which transformed a health matter into a moral judgment about character. Several participants reported that hepatitis B was routinely confused with HIV, causing it to inherit the severe stigma historically attached to that condition. Underlying these misconceptions was a perception of hepatitis B as an unclean disease, framing affected individuals as contaminated and justifying social exclusion.

Chinese Communities: Transmission Fears and Social Exclusion

2 Chinese participants in the interviews explained how, stigma manifested primarily through fears about transmission, often rooted in inadequate education about how the virus spreads. Friends expressed uncertainty about whether sharing food was safe, leading to subtle exclusion from communal meals, a practice carrying profound cultural significance in Chinese traditions.

Within families, participants observed avoidance behaviour. Once one family member began using separate utensils or avoiding physical contact, others followed suit without explicit discussion. This pattern suggests that stigma propagates through social learning, with misinformed precautions becoming embedded in household routines. Without clear, culturally appropriate education about transmission routes, participants felt unable to counter these behaviours, reinforcing their isolation.

African Communities: Chronic Illness and Confidentiality Concerns

2 interview participants from African communities identified stigma operating at a generalised level, extending beyond hepatitis B to chronic illness broadly. Living with an ongoing health condition appeared to conflict with certain cultural frameworks for understanding disease, positioning chronically ill individuals in an uncomfortable social category.

This was compounded by fears about confidentiality in healthcare settings. Participants worried their diagnosis might become known to community members working in local health services, with information travelling through informal networks to family, neighbours, or community leaders. The resulting judgment affected not only individual social standing but family reputation and prospects for marriage, employment, and community participation.

6. Partner support: critical but unsupported

Partners as the Primary Source of Support

The qualitative findings highlighted the central role that partners play in supporting individuals living with hepatitis B. 67% of interview participants identified their partner as their main or sole source of support, underscoring the extent to which informal caregiving within intimate relationships shapes the experience of living with a chronic condition. In the absence of formal support structures, peer networks, or dedicated patient services, partners often became the primary, and sometimes only, person with whom participants could discuss their diagnosis, fears, and healthcare needs.

The Nature of Partner Support

Partners provided support across multiple dimensions. Emotionally, they offered reassurance, a safe space to express fears, and validation that reduced feelings of isolation. Practically, they assisted with healthcare navigation, helping participants understand NHS systems, accompanying them to appointments, and providing medication reminders. Some partners took on advocacy roles, communicating with healthcare providers on behalf of participants or helping them articulate concerns they struggled to express independently. One participant described this multifaceted support:

> *“My partner was my biggest support system. He had already taken his vaccination… that made the conversation much easier.”*
>
> – Interview participant

This account illustrates how partner support extended beyond emotional presence to encompass practical considerations such as vaccination status, which directly affected the dynamics of being able to talk openly and ongoing intimacy.

Factors Contributing to Effective Support

Several factors emerged as critical to successful partner support. Partners who were already vaccinated reduced participants’ anxiety about transmission, removing a significant source of stress from the relationship. UK-based partners were particularly valuable for participants unfamiliar with the healthcare system, as they could help navigate NHS processes and access appropriate services. One participant noted:

> *“Partner was from the UK and provided information which helped. Partner support is key.”*
>
> – Interview participant

The quality of the partner's initial response to sharing a diagnosis proved decisive for longer-term support. Participants whose partners responded with understanding rather than fear or rejection reported substantially reduced isolation and greater willingness to engage with healthcare services. Understanding the condition accurately, rather than relying on misconceptions, enabled partners to provide informed support rather than inadvertently reinforcing stigma. As one participant reflected:

> *"She understood. I needed help in disclosing, but once I did, she was supportive."*
>
> – Interview participant

These findings align with a substantial body of research demonstrating that partner support improves outcomes across chronic conditions. Studies have consistently shown that individuals with supportive partners demonstrate better medication adherence, improved engagement withs treatment regimens, and enhanced psychological well-being (DiMatteo, 2004).[11] In the context of stigmatised conditions specifically, partner support has been associated with reduced stigma-related stress and improved quality of life (Umstead et al, 2024).[12] The mechanisms underlying these benefits include reduced isolation, increased motivation for self-care and practical assistance with disease management.

[11] DiMatteo, M.R. (2004) 'Social support and patient adherence to medical treatment: a meta-analysis', *Health Psychology*, 23(2), pp. 207–218. doi:10.1037/0278-6133.23.2.207

[12] Umstead, M., Wang, S. and Cohen, C. (2024) 'Quality of life of people living with chronic hepatitis B: the role of social support system', *PLOS Global Public Health*, 4(4). doi:10.1371/journal.pgph.0003103

7. Clinical care vs system navigation

90.9% of respondents were satisfied with clinical care, yet qualitative research revealed significant friction in system navigation. The gap is not in medical expertise, but in holistic support and inter-service communication.

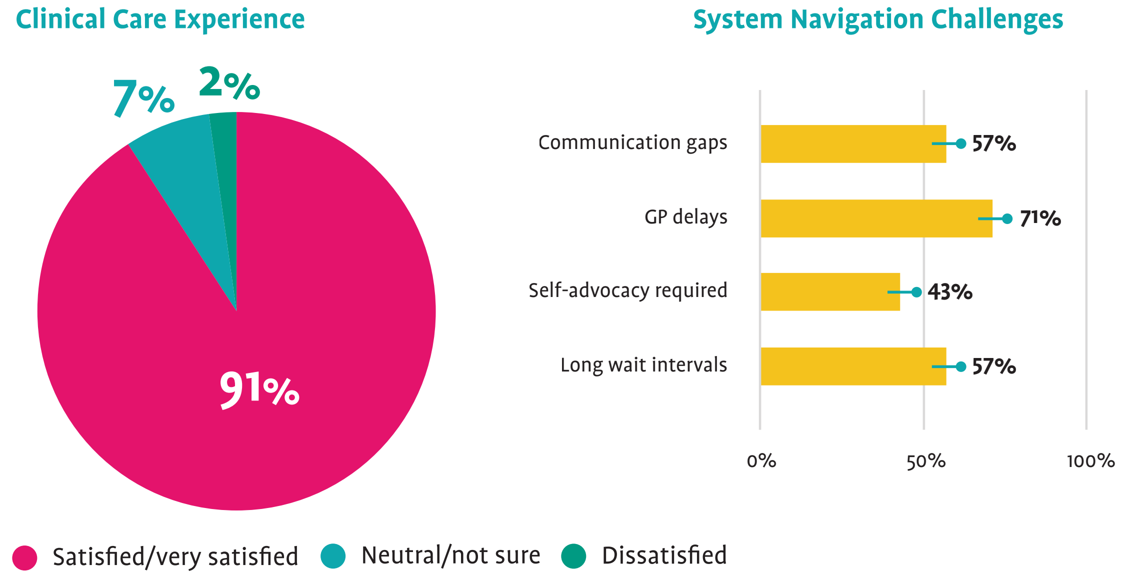

Fig 8. Clinical care experience and System navigation challenges from the questionnaire

What Is Working Well

Clinical services received strong positive feedback from questionnaire respondents. 78% of respondents indicated that they attend their appointments regularly, with a further 83% indicating they had no barriers stopping them from attending hospital appointments.

Specific aspects praised by patients:

- Regular monitoring appointments and scheduled check-ups
- Helpful, kind, and understanding clinical staff
- Clear explanations during consultations
- Thorough blood tests and scan monitoring
- Improved collaborative care post-COVID (multiple consultants, more opinions)

> *“Over time, consultations have gotten better as more conversations with patients are held, and staff are eager to enquire about testing/screening – feels more involved than ever before… younger doctors are eager.”*
>
> – Interview participant

Metric	Result	Detail
Overall Satisfaction	90.9%	Satisfied or Very Satisfied with clinic care
Regular Attendance	78.2%	Regularly attend hepatitis B appointments
No Access Barriers	83.6%	Report no challenges stopping them from attending their appointments

Table 1. Satisfaction with clinical care, attendance and access barriers

System Navigation Challenges

Despite high clinical satisfaction, qualitative research revealed significant systemic barriers.

Detailed Challenges Identified

Table 2. Challenges in accessing care amongst interviewees.

Challenge	Patient Experience
GP as Gatekeeper	1 interview participant reported having to negotiate with receptionists, repeatedly prove their condition, and beg for referrals or tests. Another participant waited 6 months for their family to get tested, despite the hospital's request.
Communication Gaps	Poor communication between GP and specialist services. 1 interview participant highlighted how their GP did not communicate with them, and after follow-up, they realised the GP had lost their referral. *"The GP as the middleman seems to be an issue... lack of communication between services."* Another participant talked about how they were not updated for a long time about the outcome of their blood and liver tests. *"I have not been updated after my blood test and liver test."* *"Why would I lie about having hep B? There should be a direct line between GP and Hep B services... It's very bureaucratic."*
Long Intervals between appointments	1 questionnaire respondent highlighted how appointment gaps of 6-12 months are perceived as too long. *"I think the gap of 12 months is too much between appointments."*
Self-Advocacy is Required	1 interview participant felt they must take extra initiative to chase results, remind services, and advocate for family testing. *"Whoever has Hep B needs a family member or loved one to keep on top of things."*
Family Testing Gaps	Despite the hospital recommending family testing for close contacts, follow-through has been inconsistent. *"Immediately said family should get tested, but my husband received nothing. No one has followed up."* 1 interview participant described repeatedly having to chase her GP to get her son tested for hepatitis B, despite the hospital having already sent a referral message. When her son was later seen by the GP for an unrelated illness, she discovered the message had been received but never acted on. *"Why do I have to keep proving everything?..I was so sad."*

Summary and Recommendations

Summary

This research provides valuable insight into the experiences, challenges, and support needs of people living with hepatitis B in Greater Manchester. Through questionnaires and in-depth interviews, a clear picture emerges: while clinical care is highly valued, with 90.9% of respondents satisfied with their treatment, significant gaps exist in the holistic support surrounding that care.

Six in ten participants were never offered emotional support, nearly half received no educational materials at diagnosis, and over three-quarters expressed a desire for peer support that does not currently exist. Qualitative interviews revealed deeper, often hidden barriers: cultural misconceptions about transmission, stigma that forces people to live a double life, and most critically, immigration-related fears that are driving individuals away from healthcare entirely, even those with secure legal status.

Recommendations

The recommendations that follow build on the study findings, outlining a pathway to address the remaining gaps in peer support, emotional care, partner support, system navigation, and, urgently, the hidden population lost to immigration fears.

1. Develop and Disseminate a Comprehensive Information Resource

For: NHS hepatitis services, MFT, commissioners, GP practices, community organisations

Many participants described leaving their initial appointment with little clarity about what hepatitis B is, how it affects the body, or what steps they must take next. With 43.6% of surveyed individuals reporting they received no information materials, and 32.7% stating they had never heard of hepatitis B prior to diagnosis, it is essential that accurate, accessible information becomes a routine part of the care pathway.

This research has already translated into action. The Living Well with Hepatitis B guide was developed by BHA for Equality in partnership with Manchester Foundation Trust and informed directly by community voices. The guide now provides the accessible, myth-busting, culturally sensitive resource that participants asked for. This demonstrates what is possible when services and communities work together.

The guide aims to dispel myths, reduce fear, and help people navigate the emotional and practical challenges of diagnosis. Because many individuals turn to the internet and encounter unreliable or frightening information, the guide also serves as a trusted source patients can return to repeatedly.

Proposed Interventions:

i) Translate the guide into priority languages, including Urdu, Mandarin, Arabic, and others identified in the survey.
ii) Distribute the guide widely across hepatitis clinics, GP practices, community centres, international student support hubs, and refugee or migrant organisations.
iii) Develop complementary video content that communicates key messages in plain language, with subtitles.
iv) Play videos in clinic waiting areas to reinforce understanding while patients wait.

2. Establish a Peer Support Programme

For: BHA for Equality, NHS hepatitis services, MFT, commissioners, peer support organisations

Participants consistently emphasised the emotional burden of living with hepatitis B, often describing feelings of secrecy, fear, and loneliness. Many expressed a desire to speak with ‘someone like me’ who understood their situation. A peer support programme can respond to this need by creating safe spaces for shared experience, reassurance, and practical advice.

The programme should be designed with cultural relevance and privacy in mind. Because some participants feared stigma or unwanted exposure, anonymity and language matching are important considerations.

Proposed Interventions:

i) Train peer support workers from communities most affected by hepatitis B, ensuring linguistic and cultural representation.
ii) Embed peer supporters in hepatitis clinics so patients can receive real-time support during appointments.
iii) Develop an anonymous online forum where participants can connect using pseudonyms and share their experiences safely.
iv) Offer virtual (Zoom) and telephone-based peer sessions, recognising that different individuals will have different levels of digital access and comfort.
v) Pilot themed groups (e.g., new diagnosis group, women only, language-specific groups) to meet diverse needs.
vi) Integrate the offer or referral for peer support into the clinical touchpoint from the point of referral and ongoing care.

3. Integrate Emotional Support into the Care Pathway

For: NHS hepatitis services, GPs, commissioners, mental health services

The emotional impact of hepatitis B was one of the strongest themes across interviews. With 60% of respondents reporting they had never been offered emotional support, and many describing feelings of isolation or "living a double life", emotional well-being must become a routine component of clinical care rather than an optional add-on.

Many people, particularly from migrant or minoritised communities, carry additional emotional burdens such as stigma, cultural expectations, trauma histories, or mistrust in institutions. By integrating emotional support early, healthcare services can reduce distress, improve adherence, and strengthen long-term engagement.

Proposed Interventions:

i) Offer emotional support at the point of diagnosis, normalising help-seeking and acknowledging the psychological impact.
ii) Provide cultural competency training for clinical staff to help them understand stigma, shame, and cultural beliefs surrounding liver disease and sexual health.
iii) Establish referral pathways to culturally appropriate mental health services (including multilingual counsellors and community embedded therapists).
iv) Make emotional support visible through posters, leaflets, and waiting room videos to signal that it is a standard part of care.

4. Improve System Navigation and Communication

For: NHS hepatitis services, GPs, MFT, NHS Greater Manchester Integrated Care Board

Across interviews, individuals repeatedly described delays, confusion, or missed follow-ups due to unclear communication between GPs and specialist services. Some struggled to get their families tested, while others were unsure whether they needed treatment or when they were due for monitoring.

Improving system navigation is crucial not only for patient confidence but also for public health, as timely monitoring reduces the risk of complications and prevents transmission.

> *"My hospital's doctor requested my registered GP clinic to arrange blood tests for the close members of my family. Due to poor communication of the clinic, it took a year for my family to be tested. Therefore, an invitation for the blood tests drafted by the hospital should be posted to the patient so they can request for the blood test with the test instead."*
>
> – Questionnaire respondent when asked how the service can be improved

Proposed Interventions:

i) Provide GPs with a simplified clinical pathway, ensuring consistency across Greater Manchester.
ii) Create direct referral pathways between hepatitis teams and GPs to avoid delays caused by administrative bottlenecks.
iii) Introduce automated family testing processes, including standardised invitation letters that patients can give to their household contacts. This can be in the form of an online home testing offer. Such an offer already exists for hepatitis C, but not for hepatitis B.
iv) Implement proactive appointment reminders in preferred languages, sent before appointments, after missed appointments, and before test deadlines.
v) Be aware of the information needs of patients on diagnosis and provide information in a timely and meaningful manner.

5. Develop Partner and Carer Support Services

For: NHS hepatitis services, BHA for Equality, community organisations

Partners and family members often play a pivotal role in supporting adherence, emotional health, and daily wellbeing. Yet many participants reported receiving no guidance on how to discuss hepatitis B with their partners or how their diagnosis might affect intimacy, fertility, or family planning.

One participant shared that his girlfriend “didn’t feel comfortable at the beginning,” while another said she wished she had guidance on how to talk to her partner. Several emphasised the practical role their partner played: “Whoever has Hep B needs a family member or loved one to keep on top of things.”

Providing structured support for partners not only improves patient outcomes but also strengthens relationships and reduces fear and misinformation.

Proposed Interventions:

i) Include information from trusted resources on how to talk to your partners, family members and friends about your diagnosis and living with hepatitis B
ii) Create and signpost to dedicated materials for partners and carers, explaining hepatitis B in accessible, culturally sensitive terms.
iii) Train clinicians how to support people in talking about living with hepatitis B and, offer to involve partners in appointments.
iv) Provide clear guidance on intimacy, family planning, pregnancy, vaccination of newborns, and cohabitation.
v) Establish partner specific support groups or online spaces, allowing family members to ask questions and share experiences.

6. Address Immigration Related Healthcare Avoidance

For: NHS hepatitis services, MFT, commissioners, community organisations, policymakers

A critical and unexpected finding was that some individuals and families are avoiding healthcare altogether due to fears that their NHS records might be accessed by immigration authorities. One participant, despite having Indefinite Leave to Remain, believed his condition could jeopardise his status. He also noted that several family members refused NHS testing and instead relied on herbal remedies, a belief he said was “common” in his community.

This form of healthcare avoidance poses major public health risks. If Greater Manchester has an estimated 16,240 people living with hepatitis B, even a modest 5–10% avoidance rate could mean 800–1,600 individuals receiving no care and potentially unknowingly transmitting the virus within households.

Proposed Interventions:

i) Make confidentiality messaging explicit and multilingual, clearly stating that NHS medical information is not shared with immigration enforcement.
ii) Train staff to proactively address immigration concerns, as many individuals will not voice these fears unprompted.
iii) Work with trusted community organisations to reach groups who avoid statutory settings.
iv) Integrate immigration reassurance into all educational materials, including guides and videos.
v) Counter misinformation about “herbal cures” using respected community messengers and peer educators.
vi) Advocate for firewall policies that formalise the separation between healthcare and immigration enforcement.

7. Addressing Cultural Barriers and Stigma

For: BHA for Equality, community organisations, religious leaders, schools, NHS

Cultural beliefs profoundly shape how people think about hepatitis B, how they talk about it, and how they engage with care. Many reported myths around food sharing, hygiene, or sexual transmission, while others described feeling judged or labelled due to cultural narratives around liver disease.

The Living Well guide addresses many of these misconceptions, but sustained engagement is needed to shift deeply rooted cultural beliefs.

Proposed Interventions:

i) Run community level awareness campaigns, using translated materials and trusted settings.
ii) Engage community and religious leaders as health champions to normalise conversations about hepatitis B.
iii) Develop short, culturally relevant social media videos for TikTok, Instagram, WhatsApp, and YouTube.
iv) Use lived experience stories to reduce stigma and build empathy.
v) Partner with youth groups, women's groups, and international student networks, tailoring content to different audiences.

Limitations

This study has several limitations that should be considered when interpreting the findings. The sample size of 55 participants (55 questionnaire respondents, 7 interview participants) represents only a small fraction of the hepatitis B population in Greater Manchester. Recruitment also occurred predominantly through MFT North Manchester (85.5%), limiting geographic representation across the region. Additional limitations include gender imbalance (60% male), under-representation of younger adults aged 18-24 (5.5%). Despite these constraints, the findings offer valuable qualitative insights into support gaps for this population.

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Acronyms

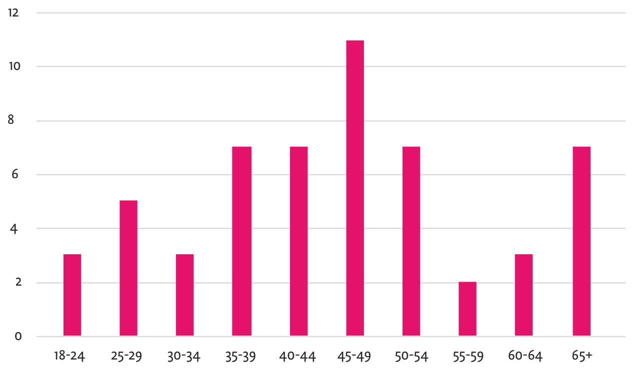
ED – Emergency Department
BBV – Blood-Borne Virus
HIV – Human Immunodeficiency Virus
GP – General Practitioner
ILR – Indefinite Leave to Remain
UK – United Kingdom

Appendix

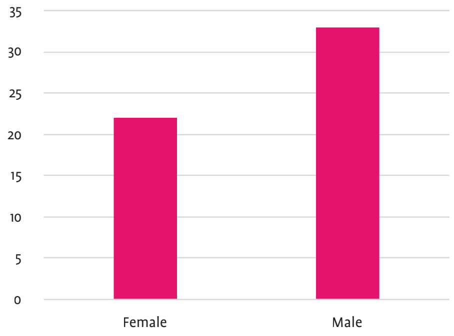
You can download a copy of the Living Well with Hepatitis B Guide at: https://thebha.org.uk/resources/

Demographics of participants involved in the research
Quantitative data
Total Sample – 55

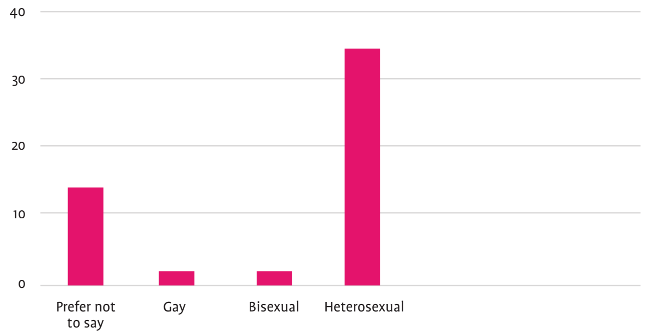
1. Age groups of participants



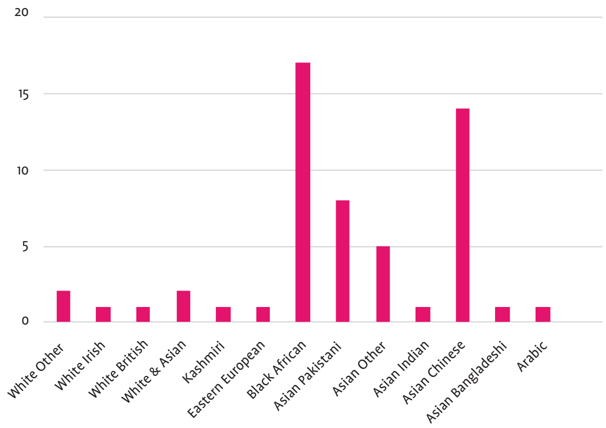
2. Participants gender



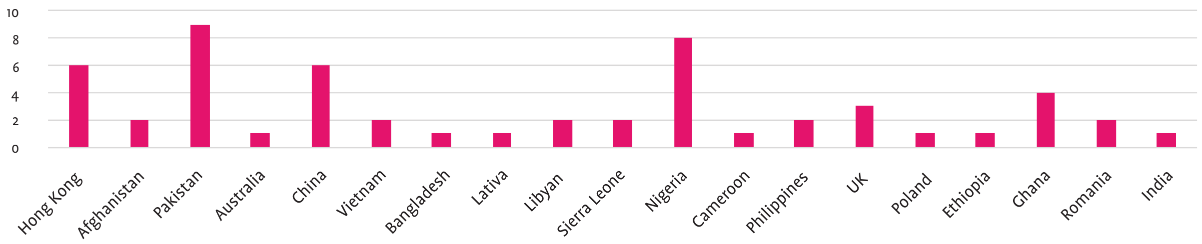
3. Sexual orientation of participants



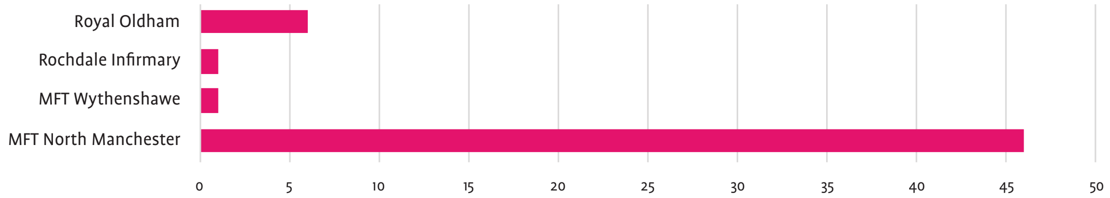
4. Participants ethnicity



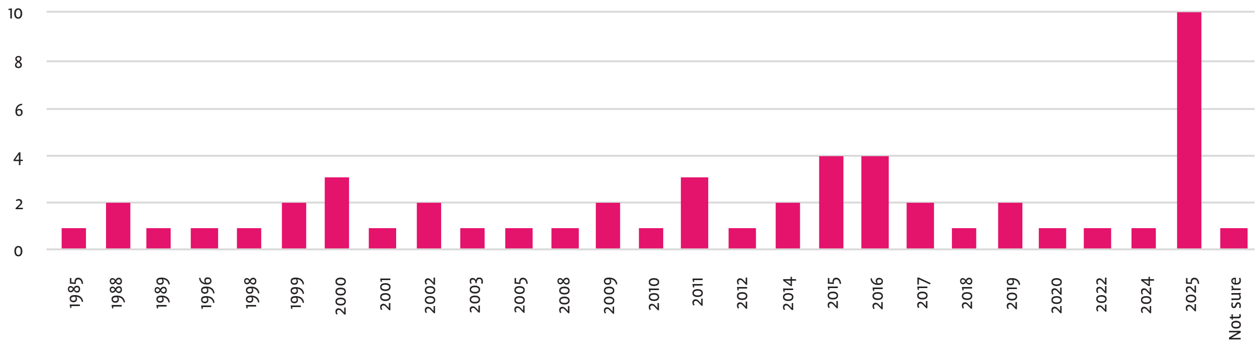
5. Participants country of birth



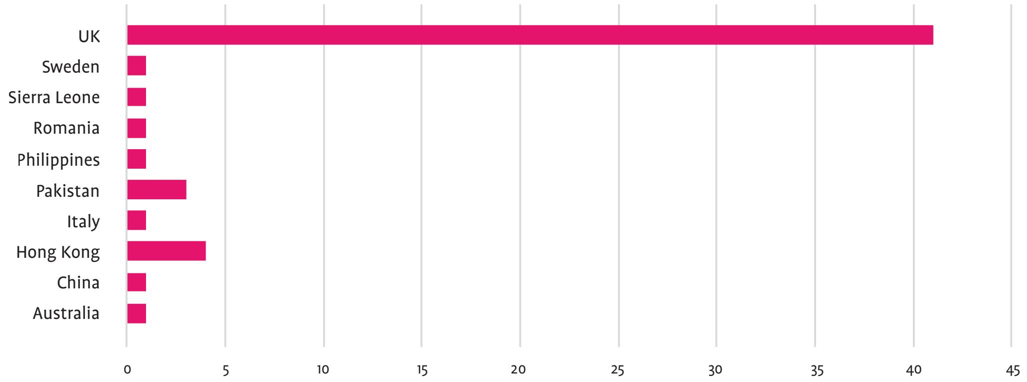
6. The service participants are currently receiving treatment from



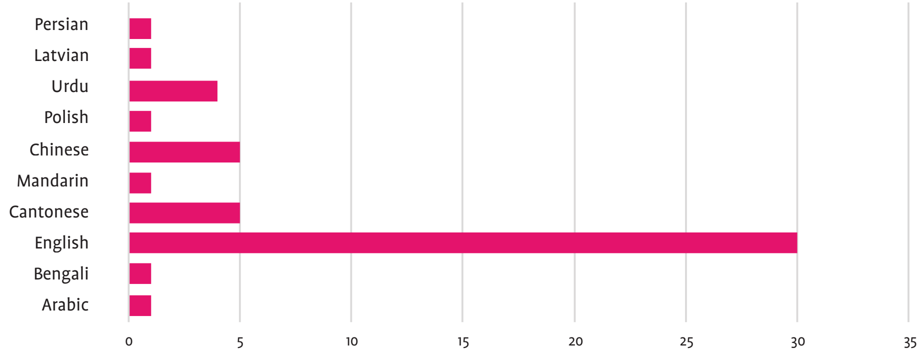
7. Participants year of diagnosis



8. Participants country of diagnosis



9. Preferred language of communication



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www.thebha.org.uk

For further support:

Visit: https://thebha.org.uk/hep-b-voices/
Follow: @bhaforequality
E-Mail: pash@thebha.org.uk
Contact: Your GP or local health team for confidential advice and testing

Learn more:

→ https://www.nhs.uk/conditions/hepatitis-b
→ https://www.hepbcompanion.org
→ https://britishlivertrust.org.uk/hepatitis-b-breaking-the-silence/
→ https://britishlivertrust.org.uk/information-and-support/liver-conditions/hepatitis-b
→ https://www.england.nhs.uk/mental-health/adults/nhs-talking-therapies
→ https://thebha.org.uk/resources
→ https://thebha.org.uk/hep-b-voices

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