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HEPATITIS
BREAK
THE
SILENCE

**Time to meet the WHO
2030 elimination goals**

Summary

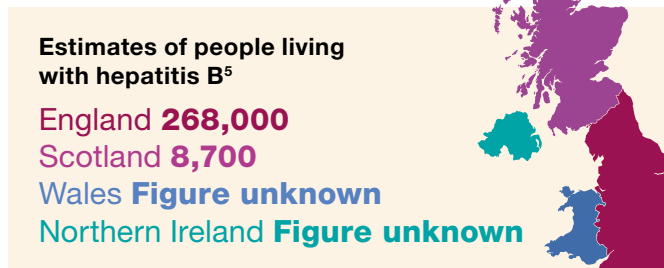
Hepatitis B is a global public health challenge which can have a devastating effect on people and communities. If left undetected, the bloodborne virus can cause cirrhosis of the liver and liver cancer. There is no cure, but effective lifelong treatment can be used to manage the virus, reducing the risk of serious disease and death. Living with hepatitis B often means uncertainty and stigma. It takes a huge toll on people's relationships and mental health, with many living in isolation and silence. However, we have the opportunity to change this to enable people to live full and active lives if we choose to take action.

In 2016, the UK Government signed up to the World Health Organization's goals to eliminate viral hepatitis by 2030¹. The UK is making good progress on hepatitis C. Time is running out to keep that promise on hepatitis B.

300 million people are living with chronic hepatitis B globally². There are 1.2 million new infections each year. Hepatitis B caused an estimated 1.1 million deaths in 2022, mostly from cirrhosis and primary liver cancer (hepatocellular carcinoma).

Hepatitis B is most commonly transmitted from mother to child during birth³. Around 90% of children who acquired acute hepatitis B will go on to develop chronic (long term) hepatitis B. In contrast, only around 5% of adults who acquire hepatitis B will develop chronic hepatitis⁴.

Anyone can acquire hepatitis B. If we are to have a health service that provides care and compassion to all at the point of need, we must ensure hepatitis B patients have equitable access to services and care, and the UK meets the World Health Organization's 2030 goals to eliminate viral hepatitis.



Hepatitis C	VS	Hepatitis B
National clinical lead and management structure in place		No national clinical lead or management structures
Elimination programme		No elimination programme
Community outreach programme for early detection		No programme
Opt out testing in emergency departments		Opt out testing in emergency departments
Strong peer support worker network		One peer support worker in London
Strong public awareness		Lack of public awareness

“The NHS has been brilliant. I go for regular check-ups every few months and live my life. In my community many people don't know about hepatitis B. I work to raise awareness so more people can get tested, diagnosed early and get treated properly.”



There are significant challenges to overcome.

- Low awareness and understanding of hepatitis B across the public, policy makers and healthcare professionals, leading to myths about the condition and entrenched stigma.
- Hepatitis B predominantly affects people from underserved communities, who already face intersectional health inequalities.
- There are significant gaps in our data, making it difficult to provide and target services or to track progress.
- A large proportion of those living with hepatitis B in the UK have either never been diagnosed or are disconnected from care.
- The UKHSA estimates that at least 50% of people living with hepatitis B in England remain undiagnosed.

There are also enablers in place and more effective medicines on the horizon.

- The NHS, UKHSA and other bodies recognise the need to act.
- The A&E opt out testing programme, introduced in 33 areas and 46 A&E departments in England, provides a scalable model to identify many of those currently undiagnosed or disconnected from care⁶. The NHSE dashboard data from April 2022 to end October 2024 (some sites have yet to report) shows 4,100 new diagnosed cases.
- There is a highly effective vaccine. We have already eliminated mother-to-child transmission for children born in the UK.
- New WHO treatment guidelines published in 2024 will significantly increase the number of people who can be offered treatment, reducing their risk of serious liver disease and liver cancer.

Our recommendations for change

The British Liver Trust are calling for significant action from the Government to meet the 2030 World Health Organization viral hepatitis elimination goals. To effectively address hepatitis B in the UK we have set out the following policy recommendations.

1. Employ a national clinical lead and structures similar to the hepatitis C elimination programme – to ensure a strategic focus on eliminating hepatitis B.
2. Extend opt out testing to all emergency departments.
3. Deliver hepatitis B testing in other community settings across the UK.
4. Establish minimum standards of care and develop new treatment guidelines to reduce variations in care.
5. Empower patients with a patient charter that clearly identifies the care they should expect.
6. Deliver an integrated national registry or data management tool to track diagnosed and treated patients, in line with the Government’s digital revolution. Ensure that ‘country of birth’ is recorded in patient records to enable better case finding.
7. Introduce peer support workers and community outreach to improve community awareness, reduce transmissions, remove barriers to care and challenge stigma.
8. Re-design services to reflect increases in the numbers of patients requiring assessment and treatment for hepatitis B. Ensure secondary care is integrated with community and primary care.
9. Implement testing and vaccination of family members of children and mothers with hepatitis B, and expand vaccinations in community settings.
10. Deliver a targeted hepatitis B public health awareness campaign to increase awareness of hepatitis B in at-risk communities and with healthcare professionals.

Hepatitis B – myths versus reality

MYTH Hepatitis B is a short-term illness that clears up by itself.

REALITY This is usually the case if you pick up hepatitis B as an adult. But if your body doesn’t fight it off within 6 months, you get a chronic infection. This is usually lifelong and can lead to serious liver disease and liver cancer. Hepatitis B becomes chronic in 90% of babies, 25-30% of young children and 5% of adults.

MYTH Hepatitis B is mostly a sexually transmitted disease.

REALITY The vast majority of people living with hepatitis B acquired it as a child. In many cases unknowingly passed on from their mother at birth.

“I lost a close friend to hepatitis B that progressed to liver cancer. His life could have been saved if he was diagnosed sooner. I’m sharing my own story to break the stigma and raise public awareness on this silent killer.”



This report has been co-produced with hepatitis B patients and developed by the British Liver Trust in partnership with clinicians from across the UK and representing all four nations.

We would like to especially thank the report’s Chair, Dr Ahmed Elsharkawy, for his continued commitment and support in the development and writing of this report. The following colleagues have also made an important and much appreciated contribution in the drafting of the report: Dr Kathryn Jack, Professor Philippa Matthews, Dr Eleni Nastouli, Dr Aneesha Noonan, Ed Nicholson, Dr Jess Carter, Dr Stuart Flanagan, Dr Stephen Barclay, Dr Neil McDougall, Professor William Irving and Professor Steve Ryder.

“I was diagnosed with hepatitis B when I was a child but it hasn’t held me back. I’m lucky ut sharing my diagnosis publicly. I don’t want my wife or daughters to get any abuse online or in school.”



MYTH Hepatitis B is a lost cause.

REALITY Current treatments for hepatitis B effectively slow down liver damage and reduce the rate of liver cancer. Vaccination already protects babies born in the UK and could protect many more people including family members of those living with the virus. If we can find people with and at risk of hepatitis B, we can help them. New treatments being developed mean a functional cure may be available in the future.

MYTH Hepatitis B isn’t a UK problem.

REALITY Hepatitis B can affect anyone, including at least 276,700 people living in the UK. Most of those people are undiagnosed and at higher risk of serious liver disease and cancer. If we are to have a health service that provides care and compassion to all at the point of need, we must ensure hepatitis B patients have equitable access to services and care.

“I was born with hepatitis B and it’s on my medical records, but I still have to explain my condition to doctors. Dating is really difficult – it’s hard to know when it’s the right time to share my condition with a partner.”



Barriers to diagnosis and treatment

To achieve the World Health Organization’s 2030 elimination goals, we need to reduce barriers to prevention, diagnosis and treatment of hepatitis B. The knowledge and expertise to properly deal with hepatitis B is lacking, with unclear roles for primary care and a secondary care-based model which is unfit for modern healthcare provision.

Many people with hepatitis B come from marginalised communities and have difficulty accessing treatment. Services need to be provided at times and in locations that make it easy for patients to access them in their local community. Telemedicine services must meet patient needs including language requirements.



~16,000 people on antiviral treatment in 2022

“There is a massive stigma around hepatitis B. When I was diagnosed, I had to wear a necklace with my blood condition. This is why it’s important for me to speak about my condition and support others diagnosed with hep B – to make sure they don’t feel alone or stigmatised.”



The health service as a whole needs to widen its knowledge of and expertise in hepatitis B. Bloodborne virus testing should be the responsibility of all clinicians. People living with hepatitis B need to receive care for other health concerns.

Many GPs provide direct care for hepatitis C patients by overseeing treatment delivery and follow-up and supporting engagement in secondary care. They also participate as GP Champions in case-finding, as well as actively engaging in research. We need to ensure collaborative working across all care settings and build on good practice for hepatitis C patients.

Health inequalities and stigma are cross-cutting issues that act as profound barriers to diagnosis and treatment.

Health inequalities

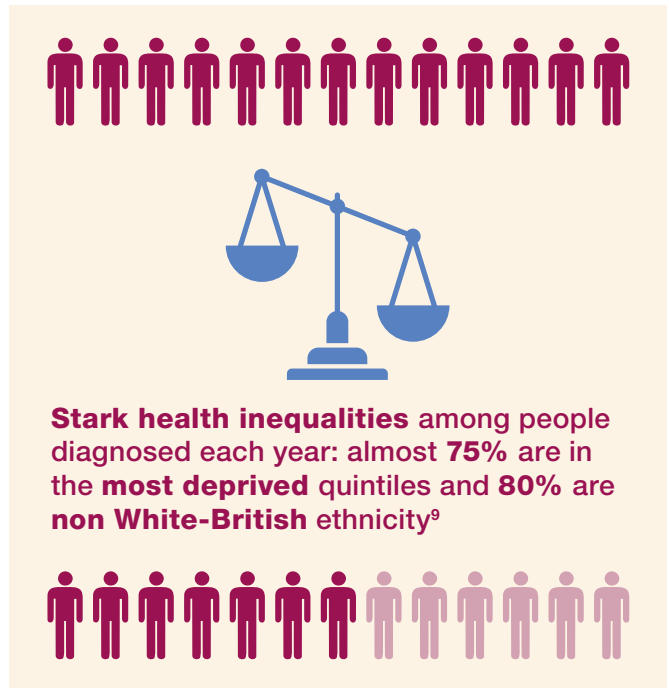
Hepatitis B disproportionately impacts our most deprived and marginalised communities. Almost two thirds of hepatitis B related end-stage liver disease and liver cancer deaths occurred among people living in our most deprived communities.

Hepatitis B disproportionately affects migrant populations, individuals from the LGBTQI+ community and people who inject drugs. There are also high levels of geographic variation, with the highest burden of disease found in ethnically diverse cities.

Wider efforts to make our healthcare system more equitable are essential in improving hepatitis B services.

Emergency Department blood borne virus opt out testing⁸ has revealed the unmet need and huge numbers of undiagnosed:

- **1,185,678 HBV tests** done
- **76%** of people tested for HBV had **no previous HBV test** (21 sites)
- Reaching **underserved** groups
- **Case-finding successful** – BUT linkage to care challenging



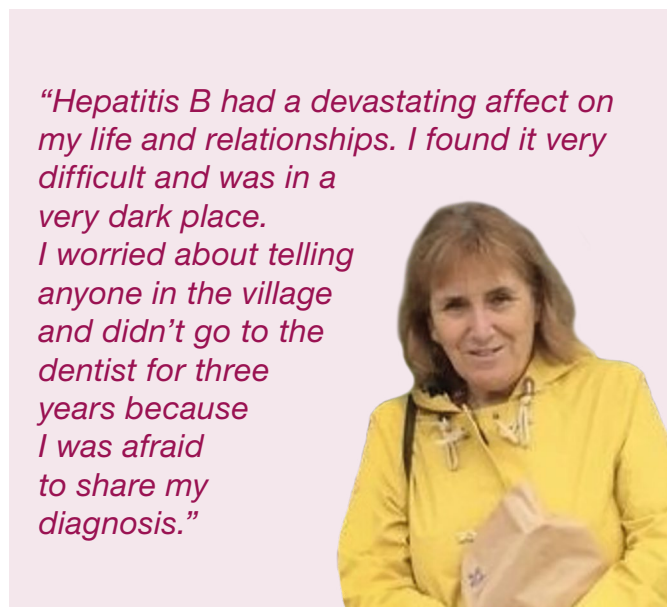
Stigma

Hepatitis B is often misunderstood as a sexually transmitted or drug-related infection, rather than an infectious disease that can on occasion be transmitted through these routes. This misrepresentation amplifies the stigmatisation of hepatitis B, worsening patients' quality of life, and potentially delaying diagnosis and treatment.

A survey by the British Liver Trust found stigma stopped a third of patients from seeking medical care¹⁰. We urgently need more good practice ambassador training in healthcare settings with a focus on lived experience. Embedded peer support workers, who understand the cultural sensitivities and needs of patients, have been shown to be effective in supporting hepatitis C and HIV patients.



Patients can be concerned that if they are diagnosed it may result in their family being tested, their immigration status being affected, or impact their visa access to other countries. We need to ensure communication with at-risk individuals is sensitive to these concerns and dispels the many myths surrounding the condition.



Data: Monitoring the challenge

The UKHSA provide annual estimates for the number of people living with hepatitis B in England. In Scotland, the latest estimate for hepatitis B infections is 8,720 in 2009¹¹. Wales and Northern Ireland do not provide estimates. Devolved nations need to provide up-to-date prevalence estimates using comparable modeling to assess if the UK is on course to meet the World Health Organization's 2030 elimination goals.

Lack of good data and systemic issues with data sharing currently lead to significant interruptions in treatment of the disease. This can have catastrophic consequences including death and patients needing a liver transplant. Effective data sharing is particularly important in hepatitis B due to its prevalence among more geographically mobile populations, such as recent migrants, asylum seekers, and people experiencing homelessness.

Acute hepatitis B infection is a '*notifiable disease*' and clinicians are required to report cases to public health for surveillance. Hepatitis B virus is a '*notifiable organism*' meaning that all positive results are reported centrally, but there is no link to care or treatment records, and therefore no way of tracking whether patients have been referred into, accessed or been retained in treatment. There needs to be a single system to allow monitoring from diagnosis through to long-term management.

Hepatitis B patient data is not universally shared between trusts and UKHSA. The Caldicott principles are often used to justify this¹². GDPR is interpreted in differing ways across the NHS. This can also have the effect of limiting data sharing. We are calling for a national registry to be set up for all patients with hepatitis B and for all Trusts to be required to share hepatitis B data with the UKHSA to allow collaboration. This is important to avoid patients being lost to care, as has happened to many patients within the UK.

The Government's ambition to move from *analogue to digital*, and for the new NHS app to provide a single point of information for patients and clinicians, will facilitate better information sharing. We need to join up primary, tertiary care, sexual health services and secondary care information, so patients are better informed, and data is more comprehensively captured to inform decision-making. Hepatitis B records including vaccinations and hepatitis B surface antibody results should, like Covid testing, be visible on patient records across all care settings. Empowering patients through improved access to their own data will better support them to manage a lifelong condition.

In Scotland, a new national clinical database will encompass both hepatitis C and B. The database will allow for seamless transfer of care between health boards and allow accurate national reporting of treatment numbers.

If we are to more accurately assess progress on hepatitis B against the World Health Organization targets, we need better data, robust modelling on the prevalence of undiagnosed hepatitis B and a national mechanism for assessing the number of diagnosed patients and the numbers eligible for and receiving treatment.

Prevention

Chronic hepatitis B is a preventable and treatable disease and there are safe and effective vaccines. Whilst there currently is no cure, safe once daily tablets are highly effective in preventing death from both liver disease and liver cancer. There are promising new functional cures in advanced clinical trials for the elimination of hepatitis B. To meet the World Health Organization elimination targets for hepatitis B, the UK Government must ensure 80% of those eligible for treatment should be receiving treatment by 2030.

There has been significant success in the uptake of hepatitis B universal antenatal screening and infant immunisation¹³. However, many family members remain unvaccinated. More progress needs to be made in the implementation and monitoring of targeted vaccinations in at-risk groups. There needs to be a significant increase in public and healthcare awareness. The UK was one of the last Western countries to implement universal infant vaccinations in 2017, meaning that the majority of the population is not protected against the virus.

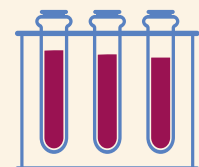
The UK Health Security Agency estimates that less than 50% of people living with hepatitis B in England have been diagnosed. Immunisation is central to preventing hepatitis B in communities at high risk. More progress needs to be made in the management of at-risk-groups and of mothers who are found to be positive, and in the targeted testing and vaccination

of family members, children, and sexual partners of individuals diagnosed with hepatitis B infection.

Integrated Care Boards and Health Boards commission services needed to address the health needs of the hepatitis B population. Commissioning bodies need to ensure sufficient resources are made available to deliver on World Health Organization 2030 goals.

~10,000 new diagnoses annually over past decade

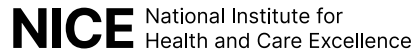
~50% living with undiagnosed HBV



Early diagnosis and effective treatment

International hepatitis B guidelines have introduced new thresholds to initiate treatment. This means a much larger proportion of people living with hepatitis will be eligible for treatment. To meet these new guidelines, the UK must expand access to treatment, workforce capacity, lifelong monitoring and community care. NHS England and the UK Health Security Agency recognise there is a large burden of undiagnosed infections, limited data on treatment initiation and retention, and falling vaccination rates across multiple groups.

International and national hepatitis B clinical guidelines set by



NHS England London Region, has developed a new hepatitis B pathway to support early diagnosis, patient engagement and retention, and improved outcomes. The work requires funding to provide patients with the care and services they need.

Launched in April 2022, opt out testing for HIV and hepatitis B in emergency departments in England has identified 4,100 people living with hepatitis B¹⁴.

New analysis of data by the UK Health Security Agency suggests that the estimated prevalence of hepatitis B is 30% higher than the previously estimated. These are patients who are not receiving treatment. It also highlights the risk of a high undiagnosed hepatitis B population and questions whether we are on track to meet World Health Organization targets.

There are also cultural issues which impact communities at-risk of hepatitis B engaging with the NHS. This can manifest in a mistrust of healthcare professionals by those communities. The transitory nature of at-risk populations mean first attendance is good but patients may be lost to care.

There needs to be wider testing of hepatitis B outside emergency settings. GP testing of at-risk patients on registration with a GP practice will improve early diagnosis. Peer support workers can help patients manage attendance at appointments and support engagement with the health system. We also need to track missed opportunities for late diagnosis and effectively share learnings across the NHS.

Liver cancer and hepatitis B

People living with hepatitis B are at a much higher risk of developing liver cancer. Liver cancer is the fastest rising cause of cancer death in the UK. The five-year survival rate for liver cancer is just 13%. Each day, 16 people in the UK die from liver cancer, which is around 6,000 people every year¹⁵.

Currently only 3 in 10 cases of liver cancer are diagnosed at an early stage (i.e. stage 1 or 2)¹⁶. If caught early, liver cancer patients have a 70-90% chance of survival for five years or more with treatment. If we are to deliver on the NHS long-term plan targets to diagnose 75% of liver cancer at stage 1 or 2 by 2028, hepatitis B early detection has to be a priority.

Hepatitis B patients with advanced fibrosis or cirrhosis should have access to regular 6 monthly ultrasound surveillance for liver cancer in line with NICE guidance¹⁷.

NHS England has pioneered good practice in expanding liver cancer surveillance to improve earlier diagnosis. The NHS England Cancer Programme (Early Diagnosis – Liver) have launched the Community Liver Health Check pilot programme which has scanned over 80,000 people and referred over 5,600 people into liver ultrasound surveillance every six months, as of October 2024¹⁸.

Hepatitis D is a viral infection that requires patients to also have hepatitis B. When both viruses are present the risk of cirrhosis and liver cancer is greatly increased. Despite the availability of new hepatitis D

treatments, testing for hepatitis D amongst those diagnosed with hepatitis B is patchy. In Scotland, reflex testing for hepatitis D amongst new diagnoses of hepatitis B takes place as standard. Such a system should be put in place in all four nations, with a lookback programme to identify and test those patients with hepatitis B who have yet to be tested.

“My hepatitis B caused liver cancer. I was extremely lucky and ended up having a liver transplant. But I often wonder if surveillance would have picked up my cancer earlier. I am passionate about raising awareness of liver cancer, which is why I’m a mentor to liver transplant patients at my hospital and an advocate for the British Liver Trust”



Living with hepatitis B often means living with uncertainty and stigma. It disproportionately affects our most marginalised communities. Too many people remain undiagnosed or are lost to care. We have the opportunity to make change and enable people to live full and active lives. Let's break the silence and meet the WHO 2030 elimination goals.

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Written questions and answers - Written questions, answers and statements - UK Parliament

Many of the patients we spoke to when developing this report did not want their image to be shown as a result of the stigma surrounding hepatitis B.



The British Liver Trust and Children's Liver Disease Foundation have merged so that we are better able to offer information and support to everyone affected by any type of liver disease throughout their lives.

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