**British Liver Trust response to the APPG on LSCs mini-inquiry**

**May 2025**

**The challenges facing earlier detection of the less survivable cancers**

***The specific systemic challenges for earlier detection and faster diagnosis of these cancers and how we can improve earlier detection throughout the patient pathway***

There are a number of critical systems challenges which can be readily addressed - and would practically improve the early detection and diagnosis of liver cancer:

* Need realistic less survivable cancer early detection targets aligned with the political cycle.
* The re-coding of liver cancer: cancer registries need to be adapted so liver cancer staging can be re-coded.
* Need to address variations in primary care pathways for liver disease. These pathways would also improve the diagnosis of liver cancer. There is wide variation in commissioned pathways[[1]](#endnote-2). We are campaigning for all ICBs to have a full pathway for the early detection of liver disease.
* Rollout of Laboratory Information Management Systems across all ICBs (which inter alia would provide a platform to host liver fibrosis assessments such as iLFTs (intelligent Liver Function Tests[[2]](#endnote-3)).
* Greater public awareness of risks associated with liver cancer and the fact it is the fastest rising cause of cancer death in the UK.
* Greater primary care awareness of risks associated with liver cancer and the use of risk stratification to identify patients.
* GP incentivisation to diagnose patients with liver disease and liver cancer as part of a fully commissioned pathway.

The less survivable cancers must be prioritised in national programmes and cancer strategies. We have a real opportunity with the development of a new national cancer plan (consultation closing on 29th April) to push for a dedicated focus on prevention and early detection of liver cancer and the other less survivable cancers.

DHSC must adopt specific targets for monitoring earlier detection of liver cancer to overcome staging challenges. Liver cancer staging is often coded through the Barcelona Clinic Liver Cancer (BCLC) staging system, which is different to the number staging system (stages 1-4) used for other cancers. This makes it harder to compare liver cancer early detection with other cancer types. When trying to apply the number staging system, 50% of hepatocellular carcinoma cases are classified as ‘unknown’ and do not capture the cancer ‘stage’ (i.e. stage 1, 2, 3 or 4) of the patient’s diagnosis. This means that the data does not enable an assessment of liver cancer against the Government’s Long Term Plan target, which aims to diagnosed 75% of people with cancer at an early stage (i.e. stage 1 or 2) by 2028[[3]](#endnote-4).

Another major systemic challenge facing the earlier detection and faster diagnosis of liver cancer is the variation in primary care pathways for the early detection of liver disease, which contributes to delayed diagnoses of liver disease, which increases

the risk of liver cancer. This is because the biggest risk factor for liver cancer is liver disease - 80-90% of HCC patients have underlying cirrhosis[[4]](#endnote-5). The results of our 2023 re-survey published in the BJGP in January 2025 found that only 36% of local health bodies had effective pathways for early detection of liver disease[[5]](#endnote-6), highlighting the ‘postcode lottery’ facing patients across the UK and the need for improvements in the commissioning of early detection pathways. The British Liver Trust is calling on all ICBs and Health Boards to implement a primary care pathway for the early detection of liver disease which includes fibrosis assessment and proactive case finding of those at high risk. Risk stratification is important because it allows healthcare providers to optimise the use of resources, ensuring that high risk patients receive priority for diagnosing liver disease, rather than applying a blanket screening of the general population which is less efficient.

Another systemic challenge impeding early detection of liver cancer is the slow rollout of updating health providers tech to support LIMS (laboratory information management system). LIMS is a tech platform which supports iLFTs (intelligent liver function tests) – which are a very effective form of fibrosis assessment.

***The systemic challenges facing patient access and referral through primary care for the less survivable cancers***

In addition to the points set out in our first response, we would add;

* Patients face barriers around stigma - societal, clinical, within the NHS and personal stigma can delay diagnosis and access to care and frustrate referrals and treatment. There is stigma around alcohol harm, obesity and viral hepatitis which impact patient outcomes and timely access to care.
* Some causes of liver cancer, such as hepatitis B, affects some of the most mobile, marginalised and vulnerable communities in the UK. This can impact these patients access to diagnosis, care and treatment, and their retention in care.
* Liver cancer is asymptomatic at the early stages.

Patients often face barriers in accessing timely referrals due to a lack of symptoms at the early stages of liver cancer as well as a lack of awareness around the risk factors of liver disease and liver cancer among patients and primary care clinicians. Only 30% of liver cancer cases are diagnosed early at stages 1 or 2[[6]](#endnote-7). There is also a lack of diagnostic tools in primary and community care which can be used to detect liver disease earlier, when interventions are most effective. We are calling for Government funding to support the rollout of fibrosis assessment tools such as non-invasive liver scans and advanced blood tests in primary care (GPs) and community settings (Community Diagnostic Centres) to improve early detection.

***How referral routes, diagnostic capacity, and access to GP appointments can be improved for those with suspected symptoms of a less survivable cancer going forward***

* The wider use of more advanced blood tests and FibroScan / transient elastography (for diagnosis).
* Wider access to ultrasound for routine surveillance.
* Risk-stratification targeted to those most at risk of developing liver cancer.
* 6-monthly surveillance for liver cancer.
* Effective recall systems.
* Hep C and B testing.

Enhancing diagnostic capacity involves investing in necessary equipment and training for healthcare providers. The British Liver Trust are advocating for increased access to fibrosis assessment tools such as non-invasive liver scans and advanced blood tests in primary care and Community Diagnosis Centres across England. We also support the continuation and expansion of NHS England’s risk-stratified Community Liver Health Check programme and Primary Care pilots to reach at-risk populations and help to identify people who require surveillance for liver cancer.

Chronic hepatitis B is a significant risk factor for developing liver cancer. According to NICE guidelines, adults with cirrhosis or chronic hepatitis B should be offered 6-monthly surveillance for HCC – yet it is estimated that less than half of people living with hepatitis B have been diagnosed[[7]](#endnote-8). Since April 2022, emergency department opt-out testing for HIV, Hep C and Hep B has newly diagnosed over 5,000 patients with Hepatitis B and found over 1,000 patients who were previously diagnosed but not accessing care. This programme is crucial to finding the undiagnosed and reaching the government’s target to eliminate hepatitis by 2030 to ensure more people at risk of liver cancer are on surveillance. However, in April 2025, some hospitals which are part of the programme were informed by NHS England that their funding will not continue for viral hepatitis at the end of the year. If this happens, it is projected that 3,300 people with Hepatitis B and hepatitis C will go undiagnosed next year. Instead of rolling back on the number of emergency departments testing for Hepatitis B and C, we advocate for this programme to be rolled out nationally and more funding should be provided to improve capacity to support those newly diagnosed.

***Practical solutions to address the lack of awareness of the often vague, hard-to-detect symptoms among individuals and healthcare professionals***

* Risk stratification: people and primary care clinicians need to be aware of the risk factors associated with liver cancer and test those patients at risk.
* Symptoms cannot be relied on as liver cancer is often asymptomatic.

A survey by the Less Survivable Cancer Taskforce found that only 1% of people can identify all liver cancer symptoms. Liver cancer is often asymptomatic in the early stages contributing to late diagnosis, and even if symptoms do present, they can be vague and non-specific; so, raising awareness of these symptoms that could indicate liver cancer is vital.

We need mechanisms for getting GPs to prioritise liver cancer – such as incentives to diagnose liver disease.

In the meantime, to improve GP education, the British Liver Trust has a free webinar on its website for primary care healthcare professionals which provides expert

specialist clinical training and essential information on how to diagnose and manage liver disease in primary care.

The NHS should signpost to charities’ patient information and resources for health care professionals.

***Learnings which can be taken from international healthcare systems on how to accelerate earlier detection***

Wales – All-Wales Abnormal Liver Blood Test pathway.[[8]](#endnote-9)

***The barriers to effective communication between patients and healthcare professionals about diagnosis, and potential measures to improve this***

The main feedback we receive as the leading liver patient charity is;

* Many patients are not provided with any information at the point of diagnosis and left with many questions around what the diagnosis means and how this will impact their life.
* There is a need for better signposting by the NHS to charity patient information.
* Stigma around the language clinicians use.

Liver cancer is often asymptomatic in its early stages, delaying diagnosis until treatment options are limited. Improving communication involves educating both patients and healthcare providers about the subtle signs of liver cancer and establishing clear referral pathways. Furthermore, Hepatitis B and D are particularly carcinogenic and often go undetected.

Once diagnosed the NHS should provide more information about what the diagnosis means and signpost to charity patient information such as the British Liver Trust booklets.[[9]](#endnote-10)

There is also a lack of policy prioritisation, possibly driven by stigma around ARLD, MASLD, Hep B and C and the fact the main risk factors for liver disease are alcohol, obesity and viral hepatitis, which are more prevalent in our most disadvantaged and marginalised communities[[10]](#endnote-11). Patients with higher socioeconomic deprivation were more likely to be diagnosed with liver cancer in an emergency setting where outcomes are particularly poor[[11]](#endnote-12). The Liao W et al. 2023 study found that compared with patients in the least deprived quintile, patients in the most deprived quintiles were more likely to be diagnosed with any liver cancer subtype, diagnosed in an emergency setting, particularly with primary liver cancer and less likely to receive any treatments (the three curative treatments, TACE, and SIRT) for any type of liver cancer[[12]](#endnote-13). It also found geographical variation in the incidence of different liver cancer subtypes; compared with London, Northwest England had a higher incidence rate for hepatocellular carcinoma and cholangiocarcinoma[[13]](#endnote-14). Liver disease mortality is five times higher in the most deprived areas compared with the most affluent.[[14]](#endnote-15)

Almost 1 in 3 people with a liver condition feel that stigma has prevented them from seeking or receiving the help they need[[15]](#endnote-16). Sadly, of the people with liver disease who

answered our survey, around half have experienced stigma from a health care professional[[16]](#endnote-17). Using patient-centred and destigmatising language is essential to encourage engagement, reduce fear, and build trust in the diagnostic process. Healthcare professional education must include updated guidance on early detection, risk factors, how to communicate a diagnosis and how to not use stigmatising language when engaging with patients.

***Evidence of new technologies, surveillance and screening programmes that have improved earlier detection and optimised referral routes, particularly among high-risk groups***

* Surveillance and screening programmes such as the NHS England liver cancer programme including the Community Liver Health Check.
* Pathways for the early detection of liver disease across all ICBs and Health Boards.
* Opt-out testing in Emergency Departments for HIV and viral hepatitis (Hep B and C)
* While we would absolutely support research and the use of new technologies, we would also highlight the role of prevention and early detection in reducing mortality rates for liver cancer and improving patient outcomes.

To help achieve the NHS Long Term Plan target to diagnose 75% of cancers at an early stage by 2028, the Early Diagnosis of Liver Cancer Programme was developed to detect more cases of HCC at an earlier, treatable stage and increase referrals and engagement of high-risk individuals with liver surveillance pathways. There are three workstreams under the NHS England liver cancer programme,[[17]](#endnote-18) including the Community Liver Health Checks.

NHS England's Community Liver Health Check programme is an example of a best practice surveillance programme that should be expanded nationally and embedded into NHS commissioning. This programme is being piloted in 19 areas of England. By taking mobile scanning units directly to high-risk communities in alcohol recovery services to food banks, sexual health clinics and homeless shelters to perform quick, non-invasive scans (FibroScans) to test for liver damage, this programme has successfully identified individuals at high risk of liver cancer, tested them for liver damage and where necessary referred them for cancer surveillance. From June 2022 to January 2025, over 93,500 FibroScans have been delivered through the pilots, with 6,421 people having enrolled into HCC surveillance[[18]](#endnote-19). The continuation and extension of this pilot would continue to improve diagnosis of marginalised and vulnerable patients.

The British Liver Trust highlights the effectiveness of non-invasive liver scans and advanced blood tests in early detection of liver disease. Another example of using technology to improve early detection is the targeted use of FibroScan in community and primary care settings – focused on high-risk groups. Variation in primary care pathways for the early detection of liver disease contribute to delayed diagnoses of liver disease, which increases the risk of diagnosing liver cancer at a late-stage. Only 20% of ICSs in England have an effective pathway for the early detection and management of liver disease i.e. only 8 of 42 ICSs have an optimal pathway in place[[19]](#endnote-20). Only 14 of 160 planned CDCs currently have FibroScan capacity for earlier detection of liver disease[[20]](#endnote-21).

People living with hepatitis B and D are at a much higher risk of developing liver cancer. Testing for adults with chronic hepatitis B and D is limited. Opt-out testing in emergency departments for HIV, hepatitis C & B is one of the most effective programmes to diagnose patients living with these conditions. Once diagnosed there are curative treatments for patients with hepatitis C and treatments and liver cancer surveillance for those with hepatitis B (where a curative treatment is currently unavailable, and first wave drugs are in development).

***Evidence and policy ideas to optimise and streamline suspected cancer referrals into the health system***

* National guidance on early detection of liver disease pathways to avoid variation in early diagnosis, referrals and access to care.
* NHSE Transformative Status for liver.

Streamlining referrals requires national guidance on early detection pathways or for all ICBs and Health Boards to commission these pathways. It also requires accessible screening programs - which is why we are advocating for the NHS England liver cancer surveillance programme pilots should be rolled out nationally.

The ongoing work in NHSE to give liver disease Transformative Status will help to unlock primary care pathways.

1. H Jarvis et al. *Increasing engagement with liver disease management across the UK: a follow-up cross-sectional survey.* BJGP Open 2025; 9 (1) <https://doi.org/10.3399/BJGPO.2024.0142> [↑](#endnote-ref-2)
2. Nobes J, Leith D, Handjiev S, Dillon JF, Dow E. Intelligent Liver Function Testing (iLFT): An Intelligent Laboratory Approach to Identifying Chronic Liver Disease. Diagnostics (Basel). 2024 May 4;14(9):960. doi: [10.3390/diagnostics14090960](https://doi.org/10.3390/diagnostics14090960) [↑](#endnote-ref-3)
3. NHS (2019). The NHS Long Term Plan. Available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf> [↑](#endnote-ref-4)
4. Nordenstedt H, White DL and El-Serag HB. The changing pattern of epidemiology in hepatocellular carcinoma. Digestive and Liver Disease 2010 42(Suppl 3):S206-14. [↑](#endnote-ref-5)
5. H Jarvis et al. *Increasing engagement with liver disease management across the UK: a follow-up cross-sectional survey.* BJGP Open 2025; 9 (1) <https://doi.org/10.3399/BJGPO.2024.0142> [↑](#endnote-ref-6)
6. Office for National Statistics (2019). Cancer Survival in England – adults diagnosed. Available at:  
   <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancersurvivalratescancersurvivalinenglandadultsdiagnosed> [↑](#endnote-ref-7)
7. <https://www.gov.uk/government/publications/hepatitis-b-in-england/hepatitis-b-in-england-2024> [↑](#endnote-ref-8)
8. <https://primarycareone.nhs.wales/news-and-events/news/all-wales-abnormal-liver-blood-tests-pathway/> [↑](#endnote-ref-9)
9. <https://britishlivertrust.org.uk/information-and-support/our-publications/download-publications/> [↑](#endnote-ref-10)
10. The rate of alcohol-specific admissions in the most deprived tenth of lower tier local authorities (835 per 100,000 population) was significantly higher than the rate in the least deprived tenth (457 per 100,000 population). [https://www.gov.uk/government/statistics/local-alcohol-profiles-for-england-lape-march-2023-update/local-alcohol-profiles-for-england-short-statistical-commentary-march-2023](https://www.gov.uk/government/statistics/local-alcohol-profiles-for-england-lape-march-2023-update/local-alcohol-profiles-for-england-short-statistical-commentary-march-2023))

    Children living in more deprived areas are substantially more likely to be obese. In 2022/23, 5.8% of children aged 4-5 living in the least deprived tenth of areas of England were obese. This compares with 12.4% of those living in the most deprived tenth of areas. <https://commonslibrary.parliament.uk/research-briefings/sn03336/>

    Prevalence of overweight (including obesity), and obesity is highest in those living in the most deprived areas (71.5% and 35.9% respectively) and lowest in those living in the least deprived areas (59.6% and 20.5% respectively) <https://www.gov.uk/government/statistics/update-to-the-obesity-profile-on-fingertips/obesity-profile-short-statistical-commentary-may-2024>

    Approximately 60% of new hepatitis B diagnoses over the 5-year period are in people residing in IMD Q1 and Q2, the 2 most deprived IMD quintiles. This underscores the association between hepatitis B infection and socioeconomic deprivation, highlighting the disproportionate burden of the disease on socioeconomically disadvantaged communities. <https://www.gov.uk/government/publications/hepatitis-b-in-england/hepatitis-b-in-england-2024> [↑](#endnote-ref-11)
11. Elliss-Brookes L., McPhail S., Ives A., et al. Routes to diagnosis for cancer - determining the patient journey using multiple routine data sets. Br J Cancer. 2012;107(8):1220–1226. <https://doi.org/10.1038/bjc.2012.408> [↑](#endnote-ref-12)
12. Liao W, Coupland CAC, Innes H, Jepsen P, Matthews PC, Campbell C; DeLIVER consortium; Barnes E, Hippisley-Cox J. Disparities in care and outcomes for primary liver cancer in England during 2008-2018: a cohort study of 8.52 million primary care population using the QResearch database. EClinicalMedicine. 2023 May 11;59:101969. doi: [10.1016/j.eclinm.2023.101969](https://doi.org/10.1016/j.eclinm.2023.101969) [↑](#endnote-ref-13)
13. Ibid [↑](#endnote-ref-14)
14. Office for Health Improvement and Disparities, premature mortality in 2022 in the most deprived vs least deprived deciles for England <https://www.gov.uk/government/statistics/liver-disease-profile-december-2024-update/liver-disease-profile-december-2024-update> and Scottish Public Health Observatory data for Scotland <https://www.scotpho.org.uk/health-conditions/chronic-liver-disease/data/mortality/>. Both accessed December 2024. [↑](#endnote-ref-15)
15. British Liver Trust. Stigma Survey <https://britishlivertrust.org.uk/stigma-survey-results/> [↑](#endnote-ref-16)
16. Ibid [↑](#endnote-ref-17)
17. <https://www.england.nhs.uk/cancer/early-diagnosis/> [↑](#endnote-ref-18)
18. <https://questions-statements.parliament.uk/written-questions/detail/2025-03-26/41674/> [↑](#endnote-ref-19)
19. [Make early diagnosis of liver disease routine - British Liver Trust](https://britishlivertrust.org.uk/soundthealarm/improving-early-diagnosis-of-liver-disease/) [↑](#endnote-ref-20)
20. [Written questions and answers - Written questions, answers and statements - UK Parliament](https://questions-statements.parliament.uk/written-questions/detail/2025-03-26/41674) [↑](#endnote-ref-21)