Written evidence submitted by British Liver Trust (FCR0065)

Introduction

The British Liver Trust is the UK's leading charity supporting people affected by liver disease and liver cancer. We welcome the committee's timely inquiry on future cancer as innovative action is urgently needed to transform survival and outcomes for liver cancer.

Liver cancer is now the fastest rising cause of cancer death in the UK[1]. Outcomes for many types of cancer have seen huge breakthroughs and improvements over recent decades. Yet deaths from liver cancer in the UK have increased by 40% in the last decade. Sadly only 13% of patients with liver cancer survive for 5 years[2].

Improving surveillance of high-risk groups with pre-existing liver disease is vital to improve survival rates as liver disease is the biggest risk factor for developing liver cancer. The establishment of a dedicated cirrhosis registry could help close severe data gaps which hamper surveillance. A registry could also support research that drives further innovation.

Expanding equitable access to minimally invasive cancer therapies (MICT) such as Selective Internal Radiation Therapy (SIRT) could have a transformative impact on liver cancer survival and outcomes and wider population health.

We urgently need the promised NHS Long Term Workforce Plan to address chronic workforce shortages in gastroenterology, hepatology, and oncology (including radiologists and specialist nurses).

Liver cancer is one of the six less survivable cancers (liver, lung, stomach, pancreatic, oesophageal and brain cancers), which account for over 40% of commons cancer deaths in the UK[3]. If the Government is to deliver on the NHS long term plan pledge to diagnose 75% of all cancers at an early stage by 2028, less survivable cancers will need to be addressed.

The UK has the potential to be a world leading global hub in liver cancer prevention, surveillance, diagnostics, and treatment. Early diagnosis of liver disease is key as liver cancer is asymptomatic in the early stages and a diagnosis of cirrhosis is the biggest risk factor for developing liver cancer.
NHS England Cancer Programme (Early Diagnosis – Liver) have launched the Community Liver Health Check pilot programme which is on track to reach 22,000 people within its first year[4]. In March 2023, the Government pledged to roll out non-invasive liver fibrosis tests (FibroScans) across 100 Community Diagnostic Centres by March 2025[5].

1. What are the innovations with the greatest potential to transform cancer diagnosis and treatment in the short, medium and long term?

The innovations with the greatest potential to transform liver cancer diagnosis and treatment are (1) targeted use of Intelligent Liver Function tests and FibroScans to identify high-risk groups for surveillance (2) greater investment in biomarker research and (3) equitable access to innovative and minimally invasive cancer therapies.

Expanding surveillance of high-risk groups with new diagnostic tools: Liver disease is the biggest risk factor for developing liver cancer. High risk groups with pre-existing liver disease are often undiagnosed and asymptomatic and therefore not on surveillance pathways. Cirrhosis is present in about 80-90% of people with the most common type of primary liver cancer, hepatocellular carcinoma (HCC)[6].

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[1] Cancer Research UK (2021). Mortality trends over time for common cancers. Available at: https://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality/ common-cancers-compared#heading-Three (last accessed March 2023)
[2]Cancer Research UK. Liver cancer survival. Available at: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-bycancer-type/liver-cancer#heading-Two (last accessed March 2023).
[3] CRUK statistics: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type
[4] https://www.england.nhs.uk/2023/03/nhs-on-the-spot-liver-scans-find-one-in-10-people-have-liver-damage-that-could-lead-to-deadly-cancer/
[5] https://britishlivertrust.org.uk/wp-content/uploads/PO-1439696-Reply-Response-from-Helen-Whateley.pdf

Only 3 in 10 cases of liver cancer are diagnosed at an early stage (i.e. stage 1 or 2)[7]. If caught early, liver cancer patients have a 70-90% chance of survival for five years or more with treatment.

We are calling for improved pathways for the early detection of liver disease to save lives and strengthen surveillance for liver cancer. Good practice fibrosis assessments, including effective blood tests (Intelligent Liver Function tests, Enhanced Liver Fibrosis tests) and non-invasive liver scans (e.g. FibroScans) are highly cost effective and reliable in diagnosing liver disease without requiring a surgical biopsy.

We are calling for:

- **Integrated Care Systems to commission effective pathways for the early detection and management of liver disease including through case-finding of those most at risk.**
- **Adoption of Intelligent Liver Function tests as the nationally endorsed liver pathology pathway and to be rolled out across primary care.**
- **Targeted roll out of non-invasive liver fibrosis testing of high-risk individuals in Community Diagnostic Centres and in primary care.**
- **Effective surveillance to be rigorously implemented including effective recall systems and quality assurance processes.**
- **Expansion of opt-out testing for viral hepatitis (HCV, HBV) in emergency departments in areas with high risk populations to strengthen liver cancer surveillance.**

Greater investment in biomarker research to improve early diagnosis and predict treatment response: To transform outcomes and survival for liver cancer and the less survivable cancers, we need a significant increase in investment in research. Research on liver cancer is severely under-funded which has stifled innovation in treatment and diagnostics. Investment is urgently needed to improve earlier detection and reduce inequalities in care and outcomes. By setting a strategic goal for tackling liver cancer, the Government may also encourage other funders and pharmaceutical companies to invest in this area of research.

The UK has potential to be a world leading global hub for innovation in biomarkers (present in blood and urine) that are reliable signs of early-stage liver cancer. Research priorities for liver cancer include testing of new biomarkers for liver cancer diagnosis and monitoring, innovative treatments, and the identification of predictors of treatment response. Effective biomarkers to identify patients with cirrhosis, who are at risk of developing a tumour will be a step change in the early detection of patients at risk of liver cancer and ensure they receive appropriate care and surveillance.

We are calling for:

- **A high-profile Government research call to encourage researchers to focus on liver cancer.**
- **Greater funding for research into biomarkers that can accurately diagnose liver cancer at an early stage.**
- **Publication of more up-to-date and disaggregated data on liver cancer would enable more effective monitoring of Government performance against key cancer targets and patient reported outcomes.**

Equitable access to minimally invasive cancer therapies: Liver cancer is complex and every patient should have access to specialist care. Currently the only curative treatments for primary liver cancer are liver transplantation and surgical resection. However, there have been recent breakthroughs in innovative and minimally invasive cancer therapies (MICT).

Selective Internal Radiation Therapy (SIRT) is a type of internal radiotherapy to control primary and secondary liver tumours that can't be removed with surgery. Despite being approved by NICE for national roll out, SIRT is only available in 17 hospitals in England resulting in significant geographic variation in care. We are calling for every liver

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[6] Nordenstedt H, White DL, El-Serag HB (2010). The changing pattern of epidemiology in hepatocellular carcinoma. Available at: https://pubmed.ncbi.nlm.nih. gov/20547305/#:~:text=Cirrhosis%20is%20present%20in%20about,90%25%20of%20all%20HCC%20worldwide

[7] Office for National Statistics (2019). Cancer survival in England – adults diagnosed. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/ healthandsocialcare/conditionsanddiseases/datasets/cancersurvivalratescancersurvivalinenglandadultsdiagnosed (last accessed March 2023)

cancer patient to have their case discussed at one of the 23 hepatobiliary specialist centres who can advise on innovative treatments such as SIRT and clinical trials to reduce variation in care.

A number of effective new medicines for liver cancer have also been made available to NHS patients in recent years, including through the Government's Cancer Drugs Fund and NICE are currently appraising several new medicines for liver cancer treatment[8].

We are calling for:

- **Every patient to be referred to a specialist centre who can advise on innovative treatment and clinical trials to reduce variation in care.**

2. How best can innovations in diagnosing and treating cancer be transitioned into frontline clinical settings?

Early diagnosis

Liver cancer is asymptomatic in the early stages. The biggest risk factor for liver cancer is pre-existing liver disease. At the moment three quarters of people with cirrhosis are diagnosed in an emergency setting at a late stage when it is too late for effective treatment or for patients to enter liver cancer surveillance. More than half of UK adults are unaware of the risk factors for developing liver cancer[9]. Public awareness of liver cancer symptoms is very poor with only one per cent of respondents to a recent Less Survivable Cancer Taskforce survey of 2,000 people able to correctly identified all liver cancer symptoms[10].

NHS Early Diagnosis (Liver) Programme: In 2022, NHS England's National Cancer Programme launched Community Liver Health Checks (CLHCs) in 12 pilot locations[11] to identify and refer individuals at high risk of liver cancer into surveillance pathways. The programme has been effective in identifying people with cirrhosis (caused by alcohol related liver disease and non-alcohol related liver disease) and chronic hepatitis B to enable them to access 6 monthly ultrasound scans in line with NICE guidelines.

- **Evidence of impact**: Between June 2022 and January 2023, the CLHC programme has reached over 7,000 people through roaming mobile units equipped with FibroScans (non-invasive liver fibrosis tests) of which over 830 were diagnosed with cirrhosis or advanced fibrosis – the majority referred for further care[12]. The number of people scanned within the first year of the programme is expected to reach 22,000.
- **Forward momentum**: NHS England's National Cancer Programme is providing £6 million to Cancer Alliances in 2023/24 to improve liver surveillance programmes.[13] At the moment there is no cirrhosis registry so it is difficult to monitor levels of surveillance and ensure that there are effective.

Proactive case-finding using algorithms: Proactive case-finding tools enable clinicians to rapidly analyse existing test results across a population and refine search criteria to identify people with early indications of liver disease or selectively target the most at risk and hard-to-reach patients (e.g. stratifying results by deprivation indices).

- **Evidence of impact**: Somerset NHS Foundation Trust has been trialling HepatoSIGHT to identify patients before they require urgent care, and when treatments are more curative and cost-effective which is yielding promising results with dozens identified with undiagnosed liver disease who are most at risk of developing liver cancer.

Non-invasive liver fibrosis tests: Non-invasive tests for liver fibrosis (e.g. enhanced liver fibrosis(ELF) blood tests or FibroScan) are a good practice diagnostic tool for assessing liver stiffness to identify people most at risk of cirrhosis or liver cancer, including those with early stage liver disease which is undiagnosed and asymptomatic. FibroScan technology has been deployed in the NHSE Community Liver Health Checks programme.

- **Evidence of impact:** The use of non-invasive liver scans in primary and community care is correlated to improved outcomes due to lifestyle modifications including reduced alcohol consumption and improved diet. Research

[8] https://questions-statements.parliament.uk/written-questions/detail/2022-11-14/86417
[9] https://livercanceruk.org/news/survey-reveals-that-most-adults-are-unaware-of-what-can-increase-their-risk-of-liver-cancer-the-fastest-growing-cause-of-cancer-death-in-the-uk-2/
[10] https://lesssurvivablecancers.org.uk/taskforce-holds-the-second-less-survivable-cancers-awareness-day/
[11] The pilot is being delivered in partnership with the National Hepatitis C (HCV) Elimination Programme via existing Operational Delivery Networks (ODNs)
[12] https://www.england.nhs.uk/2023/03/nhs-on-the-spot-liver-scans-find-one-in-10-people-have-liver-damage-that-could-lead-to-deadly-cancer/
[13] https://questions-statements.parliament.uk/written-questions/detail/2023-01-26/133597

conducted by the Scarred Liver Project indicates that FibroScan triggers a recognition about the need to change lifestyle behaviour, with 32% of patients losing 5% of their weight and 29% reducing their alcohol consumption by 10%[14].

- **Forward momentum:** In March 2023, the government pledged to roll out non-invasive liver fibrosis tests through 100 Community Diagnostic Centres by March 2025[15]. Since April 2022, NHS England have been undertaking targeted screening of alcohol-dependent in-patients in acute and mental health services using FibroScan and Enhanced Liver Function Tests. Effective testing for cirrhosis or advanced liver fibrosis in this high risk group has been incentivised through targets set out in the Commissioning for Quality and Innovation scheme[16] .

Intelligent Liver Function Tests: Intelligent liver function tests provide an automated, algorithm-based system to further investigate abnormal liver function test (LFT) results on initial blood samples from primary care[17]. Intelligent liver function tests (iLFTs) pioneered by the University of Dundee can detect the cause and stage of liver fibrosis; fast-track the referral of urgent cases to secondary care; and automatically generate treatment management plans to empower GPs with knowledge and confidence to support patients diagnosed with liver disease in primary care.

- **Evidence of impact:** The initial iLFT pathway pilot (September 2015 to November 2016) in NHS Tayside saw a 43% increase in the number of liver disease patients diagnosed. It was found to save the NHS £3,216 per patient, per lifetime, proving cost-effective. Since becoming fully operational across NHS Tayside's primary care services in August 2018, iLFT has identified that 70% of patients could continue to be managed in primary care. The Scottish Government has identified the iLFT pathway as eligible for adoption across NHS Scotland through its Modern Outpatient Programme. [18]
- **Forward momentum:** Intelligent liver function test (iLFT) pathways are now being piloted in Birmingham, Wolverhampton, Coventry, Liverpool, North London and Fife.

Liver cancer staging and data constraints: Current liver cancer data is poorly coded. For example, 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. In its current state, data does therefore 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 2028.11 Cancer registries need to be adapted so that liver cancer staging can easily be recoded. Liver cancer is complex to stage due to the underlying cirrhosis. We are calling for staging to be included in liver cancer data recording (Barcelona Clinic Liver Cancer stage for hepatocellular carcinoma and Tumour Node Metastasis for bile duct cancer) and for this to be done in a way that allows assessment against the Government's cancer targets. Data also needs to be should be disaggregated for each of the liver cancer sub-types.

We are calling for:

- **In order to drive innovation we need a patient cirrhosis registry. A patient registry (1) will identify patients with liver cirrhosis to ensure an effective surveillance process to better track patients (2) a registry will drive innovation through informing research priorities.**
- **More liver scanning services in community and primary settings to provide early detection and surveillance services.**
- **Effective surveillance to be rigorously implemented including effective recall systems and quality assurance processes.**
- **Liver cancer diagnosis to be effectively staged and recorded. This will enable the effective assessment of liver cancer diagnosis against the Government's key cancer targets.**

3. What can be learnt about innovative cancer diagnosis and treatment from international examples of best practice?

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[14] https://emahsn.org.uk/our-work/previous-projects/1125-the-scarred-liver-project https://www.scarredliverproject.org.uk/

[15] https://britishlivertrust.org.uk/wp-content/uploads/PO-1439696-Reply-Response-from-Helen-Whateley.pdf

[16] https://www.england.nhs.uk/wp-content/uploads/2022/01/B1477-i-cquin-22-23-march-2022.pdf

[17] https://academic.oup.com/jalm/article/5/5/1090/5904301

[18] 1. National Cancer Institute (2022). Advances in liver and bile duct cancer research. Available at: https://www.cancer.gov/types/liver/research (last accessed March 2023)

The UK is ranked between 14th and 27th out of 29 countries for five-year survival for the less survivable cancers.[19] We recommend that the Government takes into account international examples of good practice in detail to inform future cancer care planning.

Recent evidence from the All-Party Parliamentary Group on Minimally Invasive Cancer Therapies highlights that MICTs are embedded in hospital cancer services in Australia and the US and that innovative cancer treatments are adopted and rolled out at a faster pace in Europe and the US[20].

4. To what extent is workforce planning keeping up with innovations in the diagnosis and treatment of cancer?

The UK government needs to address chronic workforce shortages which continue to hamper cancer care and outcomes. The Covid-19 pandemic has exacerbated delays in access to treatment, placing further pressure on services and medical professionals. To ensure that patients are able to receive treatment for liver cancer, it is essential that there are enough staff available to deliver it.

According to The Royal College of Radiologists, the UK has a 17% shortfall of clinical oncologists and a 29% shortfall of consultant radiologists[21]. There are significantly less radiologists in the UK (48 per million) than there are in Spain (112 per million) and France (130 per million) [22]. In gastroenterology specifically, a 7-9% yearly expansion is needed to overcome the current shortfall in workforce, predicted retirements and population growth[23].

We are calling for:

- **The publication of the NHS Long Term Workforce Plan with pledges to expand the gastroenterology, hepatology and oncology workforce (including radiologists and specialist nurses) to keep pace with rising liver disease and liver cancer burden.**
- **Every person with liver cancer should have access to specialist care and a Clinical Nurse Specialist or Clinical Nursing Coordinator to help them navigate the pathway and ensure continuity of care.**

5. Is the impact of innovations in cancer diagnosis and treatment on health inequalities being sufficiently taken into account?

There is a significant link between health inequalities and incidence of liver cancer, given the common aetiologies are all driven by lifestyle factors that primarily affect socioeconomically marginalised groups. Alcohol misuse and obesity are key risk factors for developing liver cancer which are most prevalent in our most deprived and disadvantaged communities.

Alcohol is a Group 1 carcinogen (alongside tobacco and asbestos) which causes at least seven types of cancer. At least 400 cases of liver cancer each year are caused by drinking too much alcohol. Obesity in combination with non-alcohol related fatty liver disease (NAFLD) has a significant multiplier effect on the risk of developing cardiovascular disease and liver, colon, breast, prostate, lung and pancreatic cancers[24].

Treatment

Tackling variation in liver cancer pathways: One of the most significant barriers to accessing minimally invasive cancer therapies such as Selective Internal Radiation Therapy is geographical variation. There needs to be standardisation and more equitable access across the country to liver cancer treatment and care. This should include

[19] Data adapted from Allemani et al., 2018, the Lancet https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)33326-3/fulltext. Note that only countries with age–standardised data were taken into account. Comparison tables here and in notes to editors. Out of the 29 selected countries the UK survival estimate ranks 14th for oesophagus, 21st for liver, 22nd for brain, 25th for pancreas, 26th for stomach, and 27th for lung

[20]https://static1.squarespace.com/static/62b2d3d11cc4af3af2e2cc2b/t/62bad76c8810ee672905bc4c/1656412020930/APPG+on+MICT+Barriers+to+Patient+Access+Report.pdf

[21] The Royal College of Radiologists (2021). RCR Clinical Oncology Census Report 2021. Available at: https://www.rcr.ac.uk/clinical-oncology/rcr-clinical-oncology-censusreport-2021

[22] Royal College of Radiologists., 2021. New RCR census shows the NHS needs nearly 2,000 more radiologists. (Accessed 12.04.23: https://www.rcr.ac.uk/posts/new-rcr-census-shows-nhs-needs-nearly-2000-more-radiologists)

[23] British Society of Gastroenterology (2022). Workforce Report 2021. Available at: https://www.bsg.org.uk/workforce-reports/workforce-report-2021/

[24] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6921701/

innovative and minimally invasive liver cancer treatments, such as interventional radiology (eg ablation, selective internal radiation therapy), which treat cancers in the liver that cannot be removed with surgery.

Recent research conducted by the All-Party Parliamentary Group on Minimally Invasive Cancer Therapies found that only a handful of Cancer Alliances are capable of running specialist MICT services which has created a postcode lottery in access to care, seen most obviously in ablative therapies which are not available outside of London or in the South of England[25].

We are calling for every liver cancer patient to have their case discussed at one of the 23 hepatobiliary specialist centres who can advise on innovative treatments and clinical trials to reduce variation in care. The case should be discussed in a timely manner by a multidisciplinary team (MDT) comprising hepatology, gastroenterology, hepatobiliary surgery, radiology, oncology and palliative care professionals.

We are calling for:

- **Every patient to be referred to a specialist centre who can advise on innovative treatment and clinical trials to reduce variation in care.**
- **Every liver cancer case should be discussed in a timely manner by a multidisciplinary team (MDT) comprising hepatology, gastroenterology, hepatobiliary surgery, radiology, oncology and palliative care professionals.**
- **National audits for liver cancer to be conducted to gain further insight into regional variations in care and treatment across the nation and inform patient service improvements.**

<u>Prevention</u>

The UK Government should place greater focus on prevention at the front end of the cancer pathway to reduce pressure on the NHS, save lives and address health inequalities[26]. Liver disease is the biggest risk factor for developing liver cancer – 90% of which is reversible through lifestyle changes, including reduced consumption of alcohol, weight loss (reducing intake of fatty, salty and sugary foods and increasing exercise) and protecting against viral hepatitis.

We are calling for upstream interventions to reduce the carcinogenic effects of the unhealthy food and drink environment. Population wide measures which regulate the affordability and accessibility of alcohol and unhealthy food are proven to more effective than individual behaviour change in reducing disease burden and addressing health inequalities[27].

We are calling for:

- **A comprehensive alcohol strategy that addresses the affordability, promotion and availability of alcohol to reduce its harm and tackle health inequalities in the long term.**
- **Improved regulation of unhealthy food and drinks high in fat, salt and sugar (e.g. reformulation, marketing restrictions) to reduce obesity related health inequalities and rising costs to the NHS and Treasury.**

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[25]https://static1.squarespace.com/static/62b2d3d11cc4af3af2e2cc2b/t/62bad76c8810ee672905bc4c/1656412020930/APPG+on+MICT+Barriers+to+Patient+Access+Report.pdf

[26] https://www.cancerresearchuk.org/about-us/we-develop-policy/manifesto-for-cancer-research-and-care

[27] https://obesityhealthalliance.org.uk/wp-content/uploads/2023/02/OHA-Health-Inequalities-Position-Statement-Final.pdf