



Insights and Key Findings:
**Hepatocellular Carcinoma
Prevention and Diagnosis
Mapping Project**



Liver cancer is the fifth most frequent cancer and the third most common cancer-related cause of death worldwide¹. In Europe, **87,000 Europeans were diagnosed with liver cancer in 2020**, and **78,000 died from it in the same year**.² These numbers have been rapidly rising since and continue to do so still, with an **expected 55% increase in incidence between 2020 and 2040** if prevention strategies are not successful.^{3,4}

Despite the devastating burden of liver cancer, its most common form, **Hepatocellular Carcinoma (HCC)**,⁵ is a **highly preventable disease**. Furthermore, when HCC is **detected early**, several treatment options are available to patients, associated with **long-term survival**.⁶ It is easy to identify patients who are at high risk of developing the disease since up to 90% of liver cancer cases occur in patients with underlying cirrhosis⁷ (scarring of the liver, which can be caused by viral hepatitis B and C, alcohol-related and non-alcoholic fatty liver disease, etc.). Despite this, **most patients are diagnosed at later stages of their disease**. To reduce the devastating burden of liver cancer and to improve patient outcomes,

better, organised prevention methods and earlier diagnosis are key. The first step toward these is a deeper understanding of the country-by-country liver cancer prevention and diagnosis status quo.

With this in mind, Digestive Cancers Europe (DiCE) carried out a research project to **map the landscape of HCC prevention and diagnosis in the European Union (EU)** and create a report and an interactive map highlighting our results. With the support of experts in the field of liver cancer, we designed an **online survey** comprised of 37 questions, which was distributed among **clinicians, patient organisations, and public health experts** between 26.03.2024 and 01.09.2024.

In total, **222 people from 20 EU Member States, and two additional European countries** participated in the survey. Our findings highlight major areas within HCC prevention and diagnosis where improvement would be necessary. This report and the accompanying **map of country-by-country data** summarise our results and showcase the need for collaborative, targeted efforts in the liver cancer field.

KEY FINDINGS

Firstly, only **10 out of the 22** participating countries could provide **up-to-date country-specific data** regarding the incidence and prevalence of Hepatitis B virus (HBV) and Hepatitis C virus (HCV) infections and HCC, as well as HCC mortality. Regular monitoring of these numbers, as well as awareness and accessibility of the data, should be a priority across Europe to allow for a clear understanding of the current situation and tracking improvements or deteriorations.

Hepatitis B and C infections are well-known risk factors for developing HCC. Hence, in line with the World Health Organisation's (WHO) targets,⁸ the European Council recommendations on vaccine-preventable cancers state that by 2023, countries should have reached **I) 95 % vaccination coverage (3rd dose) of childhood HBV vaccination; II) 95 % of pregnant women being screened for HBV; III) 95% of newborns receiving timely (within 24 hours of birth) HBV birth-dose vaccination.**⁹

Based on our results, only **11 out of the 22** participating countries **reached goal I)**, while **15 reached goal II)** and **12 reached goal III)**. Furthermore, only **13 out of the 22** countries indicated the existence of **official, organised efforts to vaccinate affected adult populations** (e.g. people who use drugs, migrants, sex workers, and men who have sex with men) against HBV,

and only approximately half of participating countries have awareness programs regarding the benefits of HBV vaccination. In order **to reach the WHO's goal of eliminating hepatitis by 2030,¹⁰ all countries should prioritise HBV vaccination efforts.** On the other hand, all participating countries except for 2 reported that HCV treatment is accessible and reimbursed locally.

Globally, an epidemiological shift has occurred in HCC risk factors from virus-related to non-viral liver disease, including alcohol-associated and metabolic dysfunction-associated steatotic liver disease.¹¹ **A little over half of the participating countries** indicated that official, organised **efforts to prevent people from developing metabolic disease** exist in their countries, **while 18 indicated** that there are official, organised **efforts to control the accessibility of alcohol and the popularity of alcohol consumption.** There is a need for more rigorous and extensive preventive measures, such as evidence-based strategies for alcohol and obesity, risk education, and consumer labeling of alcohol as a carcinogen.

Although **20 out of 22** countries have **awareness campaigns about liver disease, hepatitis, and/or liver cancer**, the awareness level of the general public about the **risk factors**, as well as **the signs and symptoms of HCC**, was, on average, perceived as poor by our participants.

Similarly, **the awareness level of at-risk populations about the signs and symptoms of HCC** was also perceived as **poor**. Importantly, **the awareness level of primary care physicians about the risk factors**, as well as **the signs and symptoms of HCC** was on average perceived as **poor to moderate** by our participants. This can lead to delayed referral to specialists and hence delayed diagnosis. **Raising awareness** about HCC risk factors and signs and symptoms **should be a priority for all stakeholders** in the liver cancer field.

Stigma is a set of negative and often unfair beliefs that a society or group of people have about something, which often leads to discrimination towards those that the stigma affects. Unfortunately, liver diseases are known to be stigmatised conditions, which leads to a decrease in patients' quality of life, as well as a decreased incentive to seek healthcare. Consequently, we decided to scope the presence of stigma as perceived by our participants. Based on their responses, in **approximately half of the participating countries**, there is a **stigma associated with HBV and HCV**. The **numbers** are **slightly lower for liver disease (all forms) and HCC**; however, they still highlight **a significant issue**. Stigma is one of the biggest hurdles in effective healthcare.¹² Hence, it should be consciously addressed through awareness-raising efforts and targeted campaigns.

All major clinical guidelines recommend surveillance every **6 months in patients with liver cirrhosis**.^{13,14}

Our findings suggest that only in **15 out of the 22 participating countries is this recommendation followed**. The most listed **hurdle** to surveillance was **clinicians not referring patients to screening tests**, followed by the lack of a patient recall system and patients not attending appointments. These obstacles need to be addressed on a national level to improve surveillance rates. It has previously been demonstrated that the percentage of cirrhotic patients undergoing biannual surveillance is merely around 43% in Europe.¹⁵ **We advise that all European countries add liver cancer to their screening scheme list for patients with liver cirrhosis.**

Early diagnosis is associated with significantly better overall prognosis and improved patient quality of life. Alarming, **in half of the participating countries, HCC is most commonly diagnosed at the Advanced (BCLC Stage C) or End (BCLC Stage D) stage**, while in most remaining countries, it is diagnosed at the Intermediate stage (BCLC Stage B), with participants from only one country uniformly indicating the most common stage at diagnosis to be Early (BCLC Stage A). These results highlight the importance of all primary and secondary prevention methods.

Multidisciplinary teams (MDTs) are integral to cancer care management, and a multidisciplinary approach has been proven to be associated with improved survival of liver cancer patients.¹⁶

Our results suggest that **the diagnosis and staging of HCC**, as well as the initial treatment plan after diagnosis, is **not always discussed by an MDT across all participating countries**. Although we acknowledge that access to multidisciplinary care for all HCC patients poses organisational challenges and cultural shifts,¹⁷ this would improve overall patient outcomes significantly.

Considering the above-described results, as well as our findings from last year's HCC treatment mapping project, **the Liver Cancer Index, DiCE encourages all European countries to place liver cancer high on their agenda**. Our results highlight significant disparities in liver cancer prevention, diagnosis, treatment, and care across Europe. All stakeholders active in the field of liver cancer must work together to raise awareness about liver cancer and **must collaboratively tackle issues such as late diagnosis and stigma**. Addressing these hurdles will significantly reduce the heavy burden of liver cancer in Europe and globally.



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