

LIVER CANCER: NO PATIENT LEFT BEHIND

White paper calling for increased equality of best practice implementation in the prevention, diagnosis and management of liver cancer across Europe



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Summary of white paper calling for increased equality of best practice implementation in the prevention, diagnosis and management of liver cancer across Europe



What is liver cancer?

Primary liver cancer is cancer that started in the liver. There is more than one kind of primary liver cancer, but the main type is called Hepatocellular Carcinoma (HCC). Around 85–90% of all liver cancers are HCCs.



What's the issue?

We are at a crossroads in our fight against liver cancer in Europe. Unfortunately, it is a fight we are currently losing. Every year, more than 87.000 European citizens are diagnosed with liver cancer, while around 78.000 die from the disease. Europe has the largest burden of liver disease in the world, with the burden expected to grow. Liver cancer costs around €4 billion each year in Europe, of which €1,2 billion relates to direct costs.

There are wide disparities across EU countries in terms of implementation of best practices and corresponding survival rates.



Why is it happening?

Increasing rates of hepatitis B (HBV) and C (HCV) infection, rising alcohol consumption, and rising numbers of people with obesity are all contributing to a 'perfect storm' of factors leading to increasing rates of liver cancer in Europe. Liver cancer can be challenging to diagnose due to lack of early symptoms, and difficult to treat due to its complexity and because many patients also have a second disease, cirrhosis of the liver.



Is there cause for optimism?

Yes. Many of the risk factors associated with liver cancer are preventable or modifiable. We are learning much more about how and when to screen for liver cancer or its associated risks, and if liver cancer is diagnosed early through screening, then the prognosis for patients is significantly better. Treatments are continuing to improve. Survival rates in countries where best practices are being implemented are significantly higher.



What can we do?

At DiCE and ELPA, we call upon all stakeholders across Europe to work together to ensure that best practices are implemented at every stage of the patient pathway in each country, giving every patient the best possible opportunity of a positive outcome.






We propose a range of recommendations across five key goals (see next page).



Who are DiCE and ELPA?

Digestive Cancers Europe (DiCE) and the European Liver Patients Association (ELPA) are two European patient advocacy umbrella organisations, who have joined forces to improve the outcomes and quality of life of liver cancer patients across Europe.

RECOMMENDATIONS

GOAL	AREA	RECOMMENDATION
 OPTIMISE KNOWLEDGE	Research on liver disease	<ul style="list-style-type: none"> • Fund and enable more research on key areas (e.g. biomarkers, liquid biopsy and hepatitis C vaccine) that could make a significant difference to patient outcomes.
	Data sharing	<ul style="list-style-type: none"> • Drive better collection and analysis of liver cancer big data, utilising cancer registries.
 OPTIMISE PREVENTION	Viral hepatitis	<ul style="list-style-type: none"> • Adhere to the Action plan for the health sector response to viral hepatitis in the WHO European Region, ensuring equitable access to recommended prevention, testing, care and treatment services for all, including: <ul style="list-style-type: none"> – Implement mass HBV immunisation (for all new-borns and high-risk groups) – Control HCV transmission (including raising awareness of link with unprotected sex and needle-sharing)/ improve screening of high-risk populations, and offer treatment – Ensure equitable access to therapies for HBV and HCV infections
	Lifestyle risk factors – alcohol smoking and obesity	<ul style="list-style-type: none"> • Implement the EU Beating Cancer Plan (BECA) to reduce the harmful consequences of chronic alcohol consumption, smoking and obesity, and promote healthy lifestyles from an early age.
	Screening	<ul style="list-style-type: none"> • Improve implementation of screening programmes to identify at-risk populations, following the EASL guidelines and/ or ESMO guidelines. Patients at high risk of developing HCC should be entered into surveillance/ screening programmes. All individuals at high risk should be screened by use of abdominal ultrasound examinations every 6 months. • Monitor the outcomes of the LiverScreen initiative to understand if detection of advanced liver fibrosis in high-risk groups within the general population, using transient elastography as screening tool, is a valid screening approach.
 OPTIMISE EARLY DIAGNOSIS	Multidisciplinary teams	<ul style="list-style-type: none"> • Ensure equal opportunity for management by a multidisciplinary team (MDT) involving hepatologists, pathologists, interventional radiologists, oncologists, hepatobiliary and transplant surgeons, nurses, and general practitioners. • Investigate the potential for online consultations to plug gaps in MDTs.
	Treatment	<ul style="list-style-type: none"> • Ensure the EASL and/ or ESMO treatment guidelines are fully implemented where possible, ensuring treatment is not delayed during evaluation, when the tumour can advance rapidly. • Assess outcomes and recommendations from the BECA/ EU platform to improve access to cancer medicines to understand which elements can be implemented in liver cancer to improve early access.
 OPTIMISE TREATMENT AND CARE	Patient health literacy and support	<ul style="list-style-type: none"> • Utilise standardised nomenclature around liver cancer across Europe. • Ensure liver cancer patients and carers/ families are informed about patient organisations in their country immediately after diagnosis. If there are no organisations in the country, direct them to DiCE/ ELPA. • Raise awareness of increased risk of liver cancer among family members and encourage sharing this information with HCPs.
	Patient involvement in research	<ul style="list-style-type: none"> • Ensure liver cancer research incorporates the patient perspective e.g. endpoints that reflect the most meaningful outcomes for patients. • Ensure there is a systematic approach to collecting real-world patient experiences and needs throughout the patient pathway.
 OPTIMISE PATIENT INVOLVEMENT AND EMPOWERMENT		

LIVER CANCER IN EUROPE: URGENT ACTION NEEDED

Europe has the
largest burden
of liver disease
in the world.



~87.000

European citizens are diagnosed with liver cancer each year



~78.000

Europeans die from the disease every year



~€4 billion

is spent every year in Europe on liver cancer

MAJOR CAUSES INCLUDE:



HEPATITIS B



HEPATITIS C



ALCOHOL



SMOKING



OBESITY

As many as **half** of
liver cancer cases
are **preventable**.

(Cancer Research UK, 2015)

Outcomes vary considerably across Europe.

CALL TO ACTION

At DiCE and ELPA, we call upon all stakeholders across Europe to **work together** to ensure that best practices are implemented at every stage of the patient pathway. We have proposed a range of recommendations across **five key areas**, aiming to optimise:



KNOWLEDGE



PREVENTION



EARLY
DIAGNOSIS



TREATMENT
AND CARE



PATIENT
INVOLVEMENT AND
EMPOWERMENT

WANT TO FIND OUT MORE?

Visit <https://digestivecancers.eu/publication/white-paper-liver-cancer-no-patient-left-behind/> or <https://elpa.eu/liver-cancer/> for the full white paper.

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For further information

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