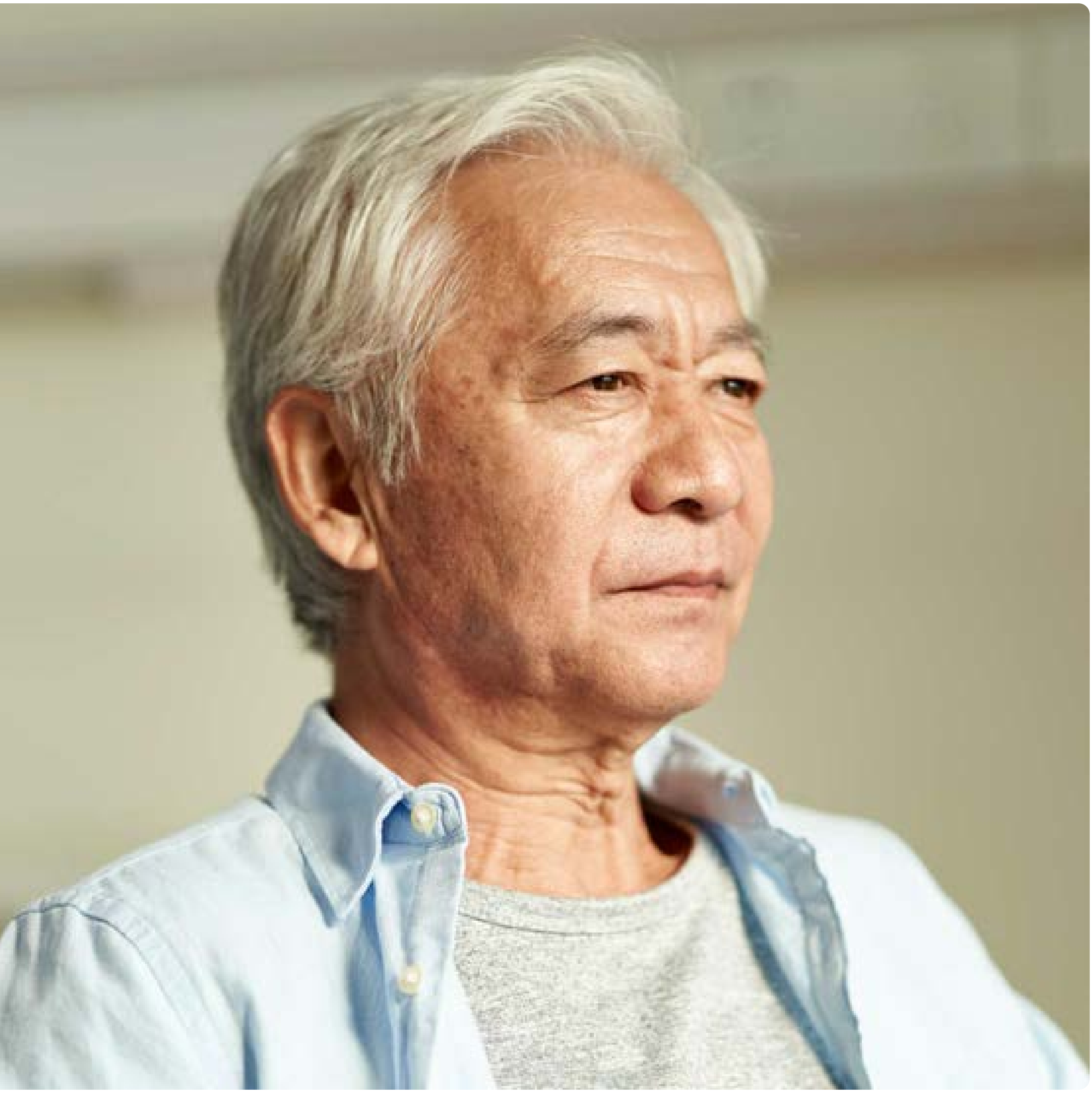
A Patient Charter for Hepatocellular Carcinoma (HCC)



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The patient charter has been co-created by a multidisciplinary group comprising of healthcare professionals, patient advocacy groups, and policymakers. The development of patient charter has been organized and funded by AstraZeneca. Please see page 3 for more details.

Foreword

Liver cancer is the sixth most common cancer worldwide and hepatocellular carcinoma (HCC) is the most common type of primary liver cancer.[1] There were approximately 866,136 new cases and 758,725 deaths worldwide due to liver cancer in 2022.[2]

People living with HCC should be empowered to live freely, without stigma and with the best possible care throughout their entire HCC journey.

It is therefore essential to raise the level of awareness of the impact of HCC and opportunities to reform patient care among people with HCC, caregivers, healthcare professionals, policymakers and the general public.

Introduction

There were 866,136 cases of liver cancer in 2022 according to the World Cancer Research Fund International.[2] HCC is estimated to account for 80% of liver cancer diagnoses worldwide.[3] Men are 2-3 times more likely than women to have HCC[4] and have a higher mortality than women.[5]

HCC most commonly develops in the context of chronic liver disease, particularly in people with cirrhosis, metabolic syndrome (chronic diabetes), Metabolic dysfunction-associated steatotic liver disease (MASLD)*, (metabolic dysfunction-associated steatohepatitis) MASH, high alcohol consumption or chronic hepatitis B and hepatitis C virus infection (HBV, HCV).[6,7] People with hepatitis D (HDV) are also at higher risk of developing liver disease and tend to suffer from liver disease that progresses rapidly.[8]

The global burden of HCC is highest in Asia and sub-Saharan Africa due to the high prevalence of chronic HBV in those regions.[9] However, deaths from HCC are also increasing in Western countries, including the United Kingdom and the United States.[10] HCC is one of the fastest-rising causes of cancer-related death in the United States and its incidence has tripled since the early 1980s.[11]

Alcohol consumption and MASLD are important drivers of this.[12] Even as global age-standardized death rates for alcohol-related liver cirrhosis declined between 2012-2017, deaths from alcohol-related liver cancer increased.[13] 35% of alcohol-related liver cancer deaths occurred in Europe in 2019.[14] The increasing prevalence of MASLD is stark, and this is driving MASLD-related HCC.[15] In the United States, this is becoming the leading cause of HCC among liver transplant candidates.[16]

There are already treatment strategies which can be potentially curative if they are started in the earlier stages of the disease.[17] Despite risk populations being well defined and the existence of available and affordable diagnostic tools, the majority of patients are still diagnosed in later stages.[18]

This charter outlines the principles of quality care that people with HCC or at risk for developing HCC should expect to receive in order to benefit from improved outcomes and increased survival. The purpose of this charter is to mobilize governments, healthcare providers, policymakers, medical societies and guideline panels, patient advocacy groups, liver cancer patients and caregivers to address the unmet need and burden in HCC. We hope that by working together we can deliver meaningful improvements in care, both now and in the future.

*** MASLD was previously referred to as Non-alcoholic fatty liver disease (NAFLD). However, in 2024 notable liver disease organizations and medical journals transitioned to MASLD as it acknowledges the root cause of the disease while using non stigmatizing language.[19,20,21]**

Seven principles of quality care for people with HCC

This Charter outlines seven principles of quality care that people with HCC should expect to receive, in order to benefit from improved outcomes and increased survival, wherever they live.

The seven principles of care are:

Principle 1:
Patients need liver cancer to be prioritized by policymakers and addressed in national cancer strategies. This must include HCC prevention through elimination of viral hepatitis as a public health threat by 2030.

Principle 2:
Patients need timely access to an early and accurate diagnosis and assessment of their HCC, leading to timely intervention and, with that, improved survival.

Principle 3:
Patients need access to a multidisciplinary team to provide comprehensive care, considering both the liver condition and cancer treatment.

Principle 4:
Patients need personalized care which considers their unique needs and preferences: taking into account personal milestones and treatment goals.

Principle 5:
Patients need shared decision-making to be recognized and implemented during their treatment pathway.

Principle 6:
Patients need access to early detection services, care, and treatment without being stigmatized.

Principle 7:
Patients need a commitment to increased funding and further research for HCC.

This patient charter was co-developed and refined through a series of multidisciplinary meetings with clinicians and patient advocacy groups. The multi-disciplinary group did not receive payment for their contribution to the charter. As part of the development process, the ILCM received compensation for chairing one roundtable meeting held in 2024.

The meetings and this charter were organized and funded by AstraZeneca.

This patient charter is endorsed by:

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The National Organization for People Living with Hepatitis B
NOPLHB

World Hepatitis Alliance

PRINCIPLE 1

Patients need liver cancer to be prioritized by policymakers and addressed in national cancer strategies. This must include HCC prevention through elimination of viral hepatitis as a public health threat by 2030

- Liver cancer is recognized as the sixth[22] most commonly diagnosed cancer and the third leading cause of cancer death worldwide.[23] Despite the fact that HCC is the most common type of primary liver cancer,[24] prioritization by policymakers is low. For example, in the UK and US like in many countries worldwide, HCC and liver cancers are often overshadowed by other cancers such as breast and lung cancers.[25]
- National strategies are essential for providing a focused and coordinated response to HCC. They ensure that resources are directed to where they can have the greatest impact; access to care is equal; research and innovation are prioritized; public awareness campaigns are instigated; and ongoing monitoring and evaluation of healthcare interventions take place.
- National strategies to address the burden of HCC should include strategies for hepatitis elimination, early detection, awareness raising and national screening programs for HCC, and ought to promote research into treatments and ensure equitable access to a range of treatments and therapies.
- The European Association for the Study of the Liver (EASL),[26] American Association for the Study of Liver Diseases (AASLD), [27] Latin American Association for the Study of the Liver (ALEH)[28] describe HBV vaccination as an essential mechanism for reducing the risk of liver cancer;[29] standardized HBV vaccine administration reduces HBV occurrence and indirectly reduces the incidence of liver cancer.[30]
- As implementation of HBV vaccination and HCV antiviral treatment programs in regions, the HCC incidence rate has decreased by 20% in Eastern and Western sub-Saharan and among the Chinese populations in Hong Kong, Shanghai and Singapore.[31] Japan, Taiwan and Egypt have also seen decreases in incidence following vaccination programmes.[32,33,34]
- The World Health Organization (WHO) notes that the “world is still far from achieving”[35] its 2030 viral

hepatitis elimination targets. This suggests that the burden of HCC has not been given the attention it fully deserves. National strategies that effectively tackle and reduce the risk of HCC will include vaccination and treatments for HBV, anti-viral therapy for HCV, treatment for HDV, along with addressing the increasing metabolic liver diseases epidemics, public education on alcohol and obesity.

- The WHO recommends birth-dose vaccination as the most effective way to prevent HBV infection and to prevent disease, such as HCC, later in life.[36] Whilst there are countries that have routine HBV birth dose vaccination programs, as of 2023, around 164 countries do not.[37] Implementation challenges in countries where large numbers of births happen outside of healthcare setting also need to be addressed.
- Access to vaccination is often driven by socioeconomic status and access to healthcare. [38,39,40] Countries with limited access need support from organizations such as the WHO, GAVI and UNICEF to increase the distribution of HBV vaccinations.[41]
- Policymakers in all countries and regions should ensure equitable access to HBV vaccination for all populations and anti-viral therapy for HCV regardless of income, education, social status or geography.

PRINCIPLE 2

Patients need timely access to an early and accurate diagnosis and assessment of their HCC, leading to timely intervention and, with that, improved survival

- Given the availability of effective interventions for HCC, health systems should prioritize identifying HCC cases early.
- Some groups of people are at higher risk of developing HCC. For example, HCC disproportionately affects racial and ethnic minorities in the US, often due to a combination of social determinants of health and systemic issues, such as limited investments into healthcare access for immigrant communities.[42]
- Between 25% and 70% of HCC patients receive their diagnosis at an advanced stage, at which point the disease is generally considered incurable.[43]
- Having effective national screening programs to identify people at high risk of HCC is essential to detect the condition as early as possible and optimize health outcomes.[44] National screening programs and other interventions that ensure a timely diagnosis may help to reduce ethnic, racial and social disparities in outcomes for HCC.[45] Screening for HBV, HCV and HDV does not only support efforts to prevent HCC but also allows healthcare providers to identify those at a higher risk of developing HCC.
- International professional bodies continue to recommend surveillance due to the fatality of late-stage diagnosis.[46] Professional society guidelines across the globe, such as EASL,[47] AASLD [48] and ALEH[49] recommend ultrasound-based HCC screening every six-months for at-risk populations and blood tests for alpha fetoprotein (AFP).[50] Screening should include people with conditions that increase the risk of HCC, including viral hepatitis, chronic liver disease[51,52] and MASLD.[53]
- HCC surveillance continues to be underused in clinical practice.[54,55] Current screening practices for high-risk populations are often suboptimal and non-existent in many countries,[56,57] with significant variations between expert and non-expert centers. As no formalized surveillance programs exist in most European countries, EASL has lobbied for the European Commission to include surveillance as part of Europe's Beating Cancer Plan.[58]

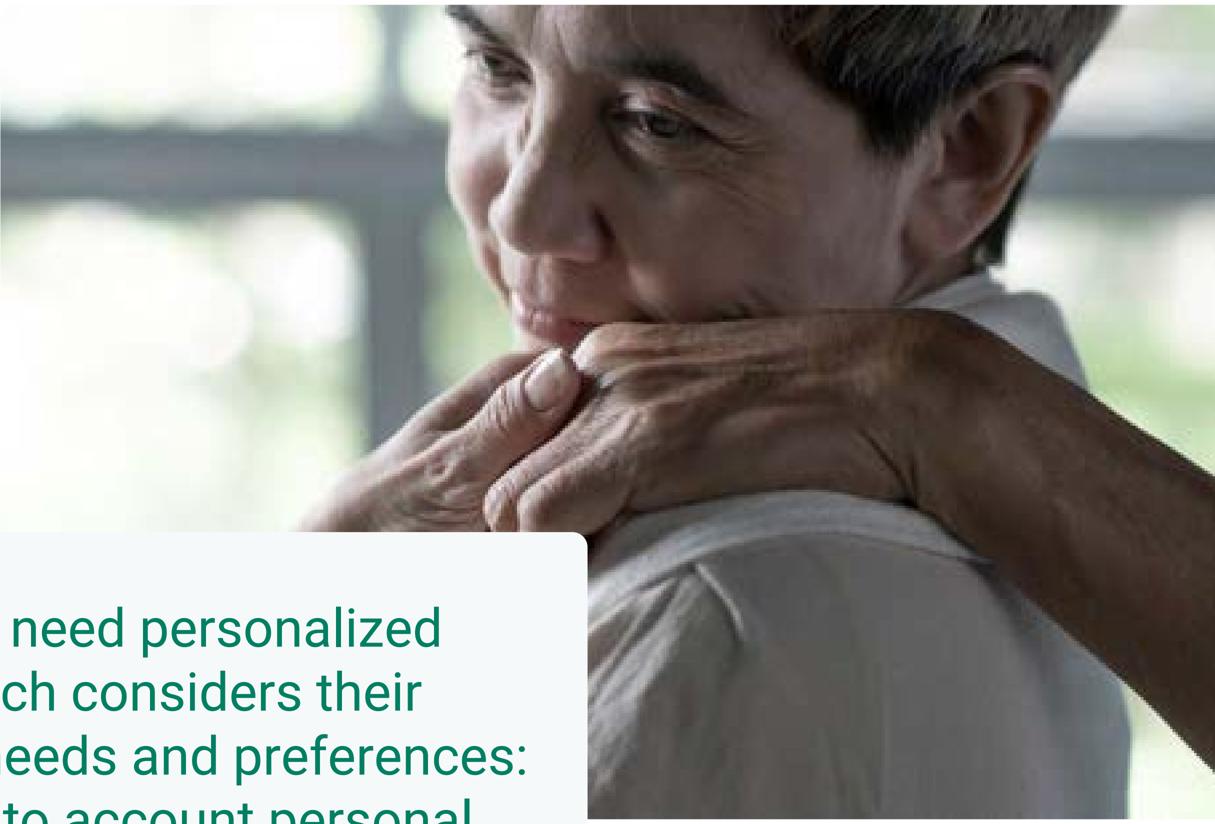
Majority of HCC patients receive their diagnosis at an advanced stage, at which point the disease is generally considered incurable

PRINCIPLE 3

Patients need access to a multidisciplinary team to provide comprehensive care, considering both the liver condition and cancer treatment

- Multidisciplinary teams, and the principles that underpin them, are critical in HCC care. They can provide a comprehensive evaluation of the HCC, develop personalized treatment plans[59] and have been shown to improve patient quality of life and overall outcomes.[60]
- The approach requires the collaboration of specialists, including epidemiologists, hepatologists/gastroenterologists, radiologists, pathologists, interventional radiologists, transplant and hepatobiliary surgeons, medical, radiation, surgical oncologists, nurse navigators, psychologists, physiotherapists, nutrition specialists, clinical pharmacologists, endoscopy doctors and palliative care providers.[61] In addition, patient support groups and patient advocacy groups play also an integral role in empowering patients and families.
- Various international guidelines, such as from AASLD, the Barcelona Clinic Liver Cancer (BCLC), Asia Pacific Association for the Study of Liver (APASL) and EASL have emphasized the importance of the multidisciplinary approach.[62,63,64,65]
- However, there are significant barriers to delivering multidisciplinary care, such as limited funding, insufficient health policies and the poor availability of specialists.[66] [67] Additionally, the operational requirements to implement effective multidisciplinary teams, such as identifying groups of patients that benefit most, identifying the ideal composition of the team and understanding the clinical outcomes,[68] have not been fully established
- Every person with HCC should have access to multidisciplinary care regardless of where they live. Even if multidisciplinary teams are not feasible due to resource restrictions, the principles of multidisciplinary care should be implemented regardless.[69] These principles could be implemented via remote or virtual multidisciplinary teams.

Every person with HCC should have access to multidisciplinary care regardless of where they live

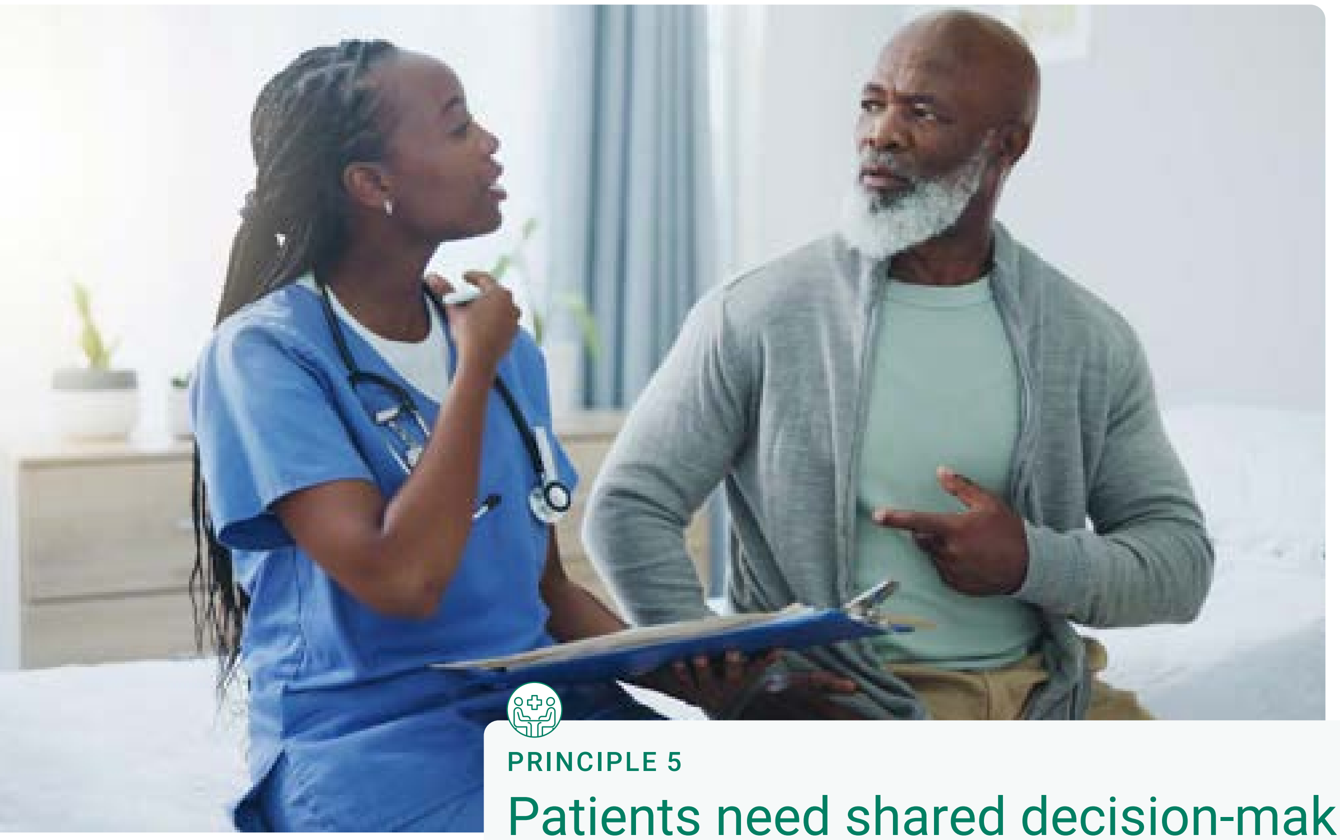


PRINCIPLE 4

Patients need personalized care which considers their unique needs and preferences: taking into account personal milestones and treatment goals

- Personalized care recognizes that each patient is unique. This is specifically important in HCC due to the significant heterogeneity of the disease and varying reactions to treatment.[70] This approach to care tailors treatment plans to each person's specific needs, preferences and circumstances. For people with HCC, this means a management approach that is individualized and customized to their overall health status; the health of their liver (cirrhosis vs. no cirrhosis and compensated or decompensated); the size, location and extent of the cancer; any other co-morbidities; patient preferences and mental health; and social circumstances and lifestyle.[71]
- The successful implementation of personalized approaches can lead to better health outcomes, more efficient service use and reduced inequalities.[72] Personalized care can also lead to reduced anxiety, quicker recovery and improved adherence to treatment programs.[73]
- Training should be provided to healthcare professionals to help personalize care plans and ensure people with HCC and their caregivers are treated with empathy and dignity, maintaining confidentiality and privacy during discussions.[74]
- Every person with HCC should have access to a personalized treatment plan. Personalized treatment plans should support self-management to ensure that people with HCC can actively participate in their care. They should include education on self-management strategies to enable people with HCC to make informed decisions, manage side effects and symptoms and, therefore, improve quality of life.

Every person with HCC should have access to a personalized treatment plan



PRINCIPLE 5

Patients need shared decision-making to be recognized and implemented during their treatment pathway

- Shared decision-making can lead to improved quality of life, outcomes, adherence and survival.[75,76] Leading guidelines from AASLD,[77] EASL,[78] and ALEH[79] suggest HCC care decisions should be made collaboratively, considering individual preferences, overall health and treatment goals.[80]
- However, people do not often feel they understand their treatment options or disease enough to participate in these discussions. For example, two-thirds of people with HCC do not feel they get enough information about their condition.[81]

Shared decision-making can lead to improved quality of life, outcomes, adherence and survival

- People with HCC must be fully informed about their treatment options to understand the risks, benefits and alternatives.[82] Information should be clear and understandable via encouraged open dialogue to address concerns and questions.[83] This information must be conveyed in patient-appropriate language, accommodating different languages and dialects where necessary and ideally using visual aids to enhance comprehension.
- Patients need to be signposted to support groups, survivor networks or peer mentors to receive this. These groups, and their work should be integral to the pathway.
- Shared decision-making tools should be implemented to facilitate discussions about preferences, values and priorities. The use of information and decision aids (e.g., brochures, videos, audio, online tools) can empower people with HCC and their caregivers and families to actively participate in decision-making.[84] Additionally, all people with HCC should be connected with support groups, survivor networks or peer mentors to support patient education, empower them to increase agency and confidently engage in shared decision-making.

PRINCIPLE 6

Patients need access to early detection services, care and treatment without being stigmatized

- Stigma surrounding liver cancer often stems from misconceptions and stereotypes associated with the disease. Many people lack information about liver cancer's causes and risk factors, leading to assumptions that HCC is a disease caused by lifestyle choices and behaviors, such as heavy alcohol use, injection drug use, obesity and cigarette smoking.[85]
- People facing this stigma may hesitate to seek medical help, fearing judgment or shame. This is actively harmful if it discourages people from getting screened for liver disease,[86] delaying diagnosis and leading to higher mortality.[87]
- Stigma also leads to an increased social and economic burden on patients and families in many regions.
- Efforts to reduce stigma must involve emphasizing that liver disease can affect people from every background, and that screening for risk factors and surveillance should be normalized.
- Challenging misconceptions and promoting education and understanding of liver disease in the general public will play a role in preventing future cases of HCC.[88]
- Equally, providing emotional support and empowerment to individuals living with liver cancer is essential. This is the genuine role of patient groups, self-help groups and survivor networks. Such support could contribute to overcoming depression caused by stigma, affecting both people with HCC and their caregivers.[89]
- Nutritional support is important in managing liver disease as it slows down its progression and the onset of complications.[90] It is also essential to address the financial strain experienced by patients and their caregivers, as this often-overlooked aspect can significantly impact their health outcomes.[91]

Stigma leads to social and economic burden on patients and families in many regions

PRINCIPLE 7

Patients need a commitment to increased funding and further research for HCC

- To ensure progress in HCC care, research funding for liver cancer must be prioritized at the same level as other cancers.
- However, current investment is disproportionately low, especially in low- and middle-income countries, where liver cancer prevalence is higher.[92]
- Most cancer biology research funding goes to institutions in high-income countries, but regional differences in cancer biology suggest findings from these institutions may not be globally generalizable.[93]
- More research is needed to improve diagnostics, treatments and data collection for HCC care. For example, there is currently no consensus on the optimal HCC screening model and further research is needed to validate novel biomarkers, genetic testing and imaging techniques for early detection.
- Research is progressing, but there is still insufficient data to reliably link molecular profiles to the most effective treatment options.
- Additionally, more comprehensive studies are needed to better understand how clinical factors, such as liver disease etiology, affect treatment responses. Enhanced data collection and registries will improve the understanding of treatment outcomes and how to optimize patient management.[94]

Enhanced data collection and registries will improve the understanding of treatment outcomes and patient management

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