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REVIEW

A Patient Charter to Improve Care for Hepatocellular Carcinoma

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Purpose: To establish a patient charter that articulates the principles of quality care for individuals living with hepatocellular carcinoma (HCC), aiming to improve patient outcomes and survival rates globally.

Methods: A multidisciplinary group comprising healthcare professionals, patient advocacy representatives, and policymakers convened to identify the critical areas of unmet need in HCC care. The group shared patient experiences, barriers, and insights – particularly with input from Patient Advocacy Groups (PAGs) – to better understand the challenges faced by patients. They reviewed existing literature, current care practices, and patient experiences to formulate a patient charter that outlines the principles of quality care for HCC.

Results: The patient charter identifies the seven principles of quality care that people with HCC or at risk of developing HCC should expect to receive in order to benefit from improved outcomes and increased survival. These principles address the need for policy prioritization, early diagnosis, multidisciplinary care, personalized treatment, shared decision-making, stigma-free access to services and increased research funding.

Conclusion: The patient charter serves as a call to action for stakeholders to unite in enhancing the care and treatment of HCC, with the ultimate goal of improving health outcomes for patients.

Keywords: hepatocellular carcinoma, liver cancer, patient care, health policy, multidisciplinary team

Introduction

HCC represents a significant global health challenge, accounting for approximately 80% of primary liver cancer diagnoses,[1] with an estimated 866,136 new cases reported in 2022 and 758,725 deaths worldwide.[2,3] The disease has a marked gender disparity, with men being two to four times more likely to develop HCC than women and also experience higher mortality rates.[4]

The pathogenesis of HCC is closely linked to chronic liver disease, particularly cirrhosis. Major risk factors for cirrhosis and HCC include metabolic syndrome (diabetes mellitus, Metabolic dysfunction-associated steatotic liver disease (MASLD), previously termed Non-Alcoholic Fatty Liver Disease (NAFLD), obesity, excessive alcohol consumption or chronic Hepatitis B (HBV) and Hepatitis C virus (HCV) infection.[5] Additionally, individuals with HBV infection who are coinfected with hepatitis D virus (HDV) often experience accelerated liver disease progression, leading to an earlier onset of HCC compared to monoinfection with other hepatitis viruses.[6]

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Despite the existence of treatment strategies that offer a good likelihood of cure when initiated at early stages,[7] the majority of HCC patients are diagnosed at advanced stages of the disease.[8] This is particularly concerning given that risk populations are well-defined and diagnostic tools are both available and affordable.

The objective of this patient charter is to outline the principles of quality care that individuals with HCC should expect to receive, with the aim of enhancing outcomes and survival rates. It serves as a call to action for governments, healthcare providers, policymakers, medical societies, guideline panels, patient advocacy groups, and those affected by HCC to collectively address the unmet needs and burdens associated with HCC. Through collaborative efforts, we aim to achieve meaningful improvements in HCC care now and for future generations.

The patient charter outlines seven key principles aimed at improving care for individuals with HCC. The patient charter's principles address the need for policy prioritization, early diagnosis, multidisciplinary care, personalized treatment, shared decision-making, stigma-free access to services, and increased research funding.

Material and Methods

Working Group Formation

The HCC patient charter was developed through a series of multidisciplinary consultations and roundtable discussions with clinicians, patient advocacy groups and healthcare professionals from across the globe. The aim was to ensure a comprehensive and representative set of principles that reflect the needs and experiences of individuals affected by HCC. The International Liver Cancer Movement (ILCM) played a pivotal role in this process, collaborating closely with us to create the charter and contributing their expertise as chairs of discussions during one of the roundtables.

Literature Review, Advocacy Advisory Board and Formulation of the Patient Charter

A literature review was conducted with the objectives of identifying current unmet needs in HCC care worldwide, understanding existing advocacy efforts, and examining best practices from other disease areas where patient charters have successfully driven change. This review provided a foundational understanding to inform the development of the patient charter.

In April 2024, an Advocacy Advisory Board was formed, comprising representatives from PAGs. The board discussed the major unmet needs in HCC as reported by the patient, clinical and advocacy community to develop specific principles to be included in the patient charter. The board reached a consensus on priority areas of unmet need, which were subsequently addressed in the patient charter's principles.

Following this, desk research was conducted to draft these principles. To validate and refine the draft principles, two multidisciplinary roundtables were held in September 2024 at the European Society for Medical Oncology (ESMO) and the World Cancer Congress (WCC). The goal was to align the patient charter with the broader HCC community's perspectives and initiate planning for its launch and dissemination.

Results

Principle 1: Patients Need Liver Cancer to Be Prioritized by Policymakers and Addressed in National Cancer Strategies. This Includes Grasping the Opportunity to Prevent Many HCC Cases by Eliminating Viral Hepatitis as a Public Health Threat by 2030, Which Would Significantly Reduce Mortality, Improve Quality of Life and Lower Healthcare Costs

Despite HCC being the most common type of primary liver cancer,[9] few policymakers prioritize HCC prevention, screening and treatment. In countries such as the United Kingdom (UK) and United States (US) – as in much of the world – HCC is often overshadowed by other cancers with more established advocacy, such as breast, colorectoral and lung cancers.[10] Yet, HCC is among the most preventable cancers. A coordinated, strategic response is essential to address this growing public health challenge.

Effective national strategies should begin with prevention and early detection. Public health campaigns must raise awareness of key risk factors, including harmful alcohol use and metabolic syndrome, while ensuring equitable access to preventive services. Central to these efforts are widespread HBV vaccination and the scaling up of testing and treatment for HBV, HDV, and HCV. These measures are not only cost-effective but lifesaving. For example, large-scale HBV vaccination and HCV antiviral therapy programs in regions such as sub-Saharan Africa, Hong Kong, Shanghai, Japan, Taiwan, Egypt and Singapore have already contributed to a 20% reduction in HCC incidence.[11,12] Despite this progress, the World Health Organization (WHO) has acknowledged that the global community is falling short of its 2030 viral hepatitis elimination targets. This highlights the need for urgent policy action. National cancer control plans must integrate HCC prevention, including expanded vaccination programs, access to curative antiviral therapies, investment in research and innovation, and public education campaigns. Without such concerted efforts, the global burden of HCC will continue to rise, and the opportunity to save thousands of lives will be lost.

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

HCC is frequently diagnosed at an advanced stage, with studies estimating that 25% to 70% of patients are identified too late, rendering the disease incurable.[13] This underscores the critical need for effective national screening programs targeting high-risk populations, which can significantly improve early detection, survival outcomes and reduce the overall disease burden. Moreover, timely diagnosis through structured surveillance may help address persistent ethnic, racial and socioeconomic disparities in HCC outcomes.[14,15]

In the US, for instance, HCC disproportionately affects racial and ethnic minority groups – often linked to broader social determinants of health and systemic barriers, including limited healthcare access in immigrant and underserved communities.[16] Establishing comprehensive screening and surveillance systems is essential to mitigate these disparities and ensure more equitable care.[14]

The success of HCC surveillance depends on several factors: the availability and acceptability of reliable diagnostic tools, timely access to treatment, healthcare provider awareness, and seamless integration into routine clinical workflows.[17] While the evidence base for HCC surveillance remains limited, the consistently high mortality associated with late-stage diagnosis has led leading international societies including European Association for the Study of the Liver (EASL),[18] American Association for the Study of Liver Disease (AASLD),[19] Asia-Pacific Association for the Study of the Liver (APASL)[20] and Asociación Latinoamericana para el Estudio del Hígado (ALEH)[21] – to recommend routine surveillance in at-risk individuals. This typically involves ultrasound imaging every six months, often coupled with -alpha-fetoprotein (AFP) blood testing.[19] Eligible populations include individuals with chronic liver disease, viral hepatitis,[19] MASLD, or a family history of HCC.[22]

Despite these guidelines, HCC surveillance remains underutilized in practice.[23,24] Screening uptake is frequently suboptimal or absent altogether, particularly in regions lacking formal national programs.[25] Disparities in implementation between specialized and non-specialized centers further contribute to delayed diagnoses. In response, EASL has urged the European Commission to incorporate HCC screening into Europe's Beating Cancer Plan, aiming to establish consistent, continent-wide surveillance protocols.[26]

Principle 3: Patients Need Access to a Multidisciplinary Team to Provide Comprehensive Care, Considering Both the Liver Condition and Cancer Treatment

Multidisciplinary teams or at least its principles are critical in HCC care. They can provide a comprehensive evaluation of the HCC, develop personalized treatment plans and have been shown to improve patient quality of life and overall outcomes.[27] These teams enable thorough assessment of both liver function and tumor burden, allowing for tailored therapeutic strategies. Core members typically include epidemiologists, hepatologists or gastroenterologists, radiologists, interventional radiologists, pathologists, transplant and hepatobiliary surgeons, oncologists, surgical oncologists, endoscopists, clinical pharmacologists, nutritionists, palliative care specialists, psychologists, physiotherapists, and nurse navigators.[28] Patient support groups and advocacy organizations also play a critical role in patient empowerment and shared decision-making.

Multidisciplinary care can be delivered at varying levels of complexity and integration. At its most basic, it involves coordinated access to relevant subspecialists within the same health system, facilitating sequential consultations. A more structured model is the multidisciplinary tumor board, in which cases are collaboratively reviewed by experts across disciplines to develop consensus treatment plans. The most integrated model features co-located multidisciplinary HCC clinics, where real-time interaction among specialists enhances communication, speeds up decision-making, and streamlines care delivery.[18,19,29,30]

Each level of multidisciplinary engagement offers benefits, and health systems should aim to implement the highest level of integration possible, adapted to local resources and patient needs. Major clinical guidelines – including those from the AASLD, Barcelona Clinic Liver Cancer (BCLC) group, the APASL, and the EASL – emphasize the central role of multidisciplinary care in HCC management.[18,19,29,30] These guidelines consistently associate multidisciplinary care with improved treatment efficacy and patient-centered outcomes.

Despite its recognized value, access to multidisciplinary care remains uneven due to systemic barriers, including funding constraints, workforce shortages, and limited institutional capacity.[31,32] Furthermore, key operational details – such as identifying which patient populations benefit most, the optimal team composition, and measurable clinical outcomes – require further clarification.[33]

Access to multidisciplinary care should be guaranteed for all patients with HCC, regardless of geographic location.[34] In regions where in-person multidisciplinary teams are not feasible, telemedicine and virtual tumor boards can help extend this collaborative model of care to underserved areas, improving equity and access to high-quality treatment.

Principle 4: Patients Need Personalized Care Which Considers Their Unique Needs and Preferences: Considering Personal Milestones and Treatment Goals

Personalized care is fundamental to optimizing outcomes for patients with HCC. Recognizing that every patient is unique, this approach tailors treatment plans to align with each individual's specific needs, preferences and circumstances.

Personalized care for people with HCC involves crafting management strategies that consider multiple factors: a patient's overall health status, liver function (whether cirrhotic or non-cirrhotic, and whether compensated or decompensated), the size, location, and spread of the cancer, co-morbidities, mental health needs, lifestyle and social circumstances.[35] Personalized care in HCC must be grounded in a thorough understanding of patient characteristics and preferences that directly inform treatment selection. While HCC predominantly affects older adults – the mean ages of diagnosis with HCC were 55–59 years in China and 63–65 years in Europe and North America[12] – there is a notable subset of younger patients, particularly in regions with endemic hepatitis B, where a greater number of HCC cases may occur in individuals at earlier ages.[12] For these younger patients, long-term life planning considerations, such as fertility preservation, can significantly influence treatment choices.[36] Cultural background, language proficiency, health literacy, and individual beliefs also shape treatment preferences and engagement.[37] By integrating these factors into care planning, clinicians can ensure that treatment strategies align not only with clinical needs but also with what matters most to each patient.

Successful implementation of personalized approaches can lead to improved health outcomes, more efficient healthcare service use, and a reduction in health inequalities.[38] Personalized care can also lead to reduced anxiety, quicker recovery and improved adherence to treatment programs, especially in cases where accepting language is effectively utilized.[35]

Every patient diagnosed with HCC should have access to an individualized care plan that reflects their unique medical and personal context, ensuring that clinical decisions are made not only for patients – but with them. Given the heterogeneity of HCC, a one-size-fits-all approach is insufficient.[39] Tailored care allows patients to receive treatments that are better suited to their specific disease state and personal goals.

Healthcare professionals should be equipped to deliver care that is both clinically appropriate and emotionally supportive. This includes training in communication, cultural sensitivity and shared decision making.[40] Maintaining patient privacy and dignity, particularly during sensitive discussions, is crucial.

Empowering patients through supported self-management is also vital. Education about the disease, symptom management, and treatment options enables individuals to play an active role in their care, improving quality of life and treatment engagement. Connecting patients with peer mentors, survivor networks, or support groups further reinforces agency and confidence in the care process.

Principle 5: Patients Need Shared Decision-Making to Be Recognized and Implemented During Their Treatment Pathway

Shared decision-making is a collaborative and empowering process where HCPs and patients jointly make care and treatment decisions, considering the diagnosis, specific disease features, personal circumstances, lifestyle and preferences. This is a continuous process, as preferences and needs can change over time.

Effective shared decision-making is essential for optimizing outcomes in HCC. Leading guidelines from the AASLD,[19] the EASL,[18] the APASL,[41] BCLC[29] and the ALEH,[21] suggest that HCC care decisions should be made collaboratively, considering individual preferences, overall health and treatment goals.[9]

Research indicates that shared decision-making can significantly enhance patient quality of life, improve clinical outcomes, increase adherence to treatment plans, and even prolong survival.[42,43] By engaging patients in the decision-making process, healthcare providers can ensure that treatment strategies align with the patient's values, priorities, and long-term goals.

Despite the benefits, many patients with HCC do not feel adequately informed to participate in their care decisions. Studies have found that up to two-thirds of people with HCC report not receiving enough information about their condition.[44] This knowledge gap can prevent patients from engaging meaningfully in discussions about their treatment options.

To enable effective shared decision-making, patients must be fully informed about the risks, benefits and alternatives of each treatment option. Open dialogue should be encouraged to address patient concerns and questions. Providing clear, patient-centered information is crucial – this includes using language that is understandable, accommodating different languages or dialects, and utilizing visual aids where necessary to support comprehension.[44]

Patients should also be connected to support networks, such as survivor groups or peer mentors, who can provide additional guidance and information. These resources should be integrated into the patient care pathway to support ongoing decision-making.

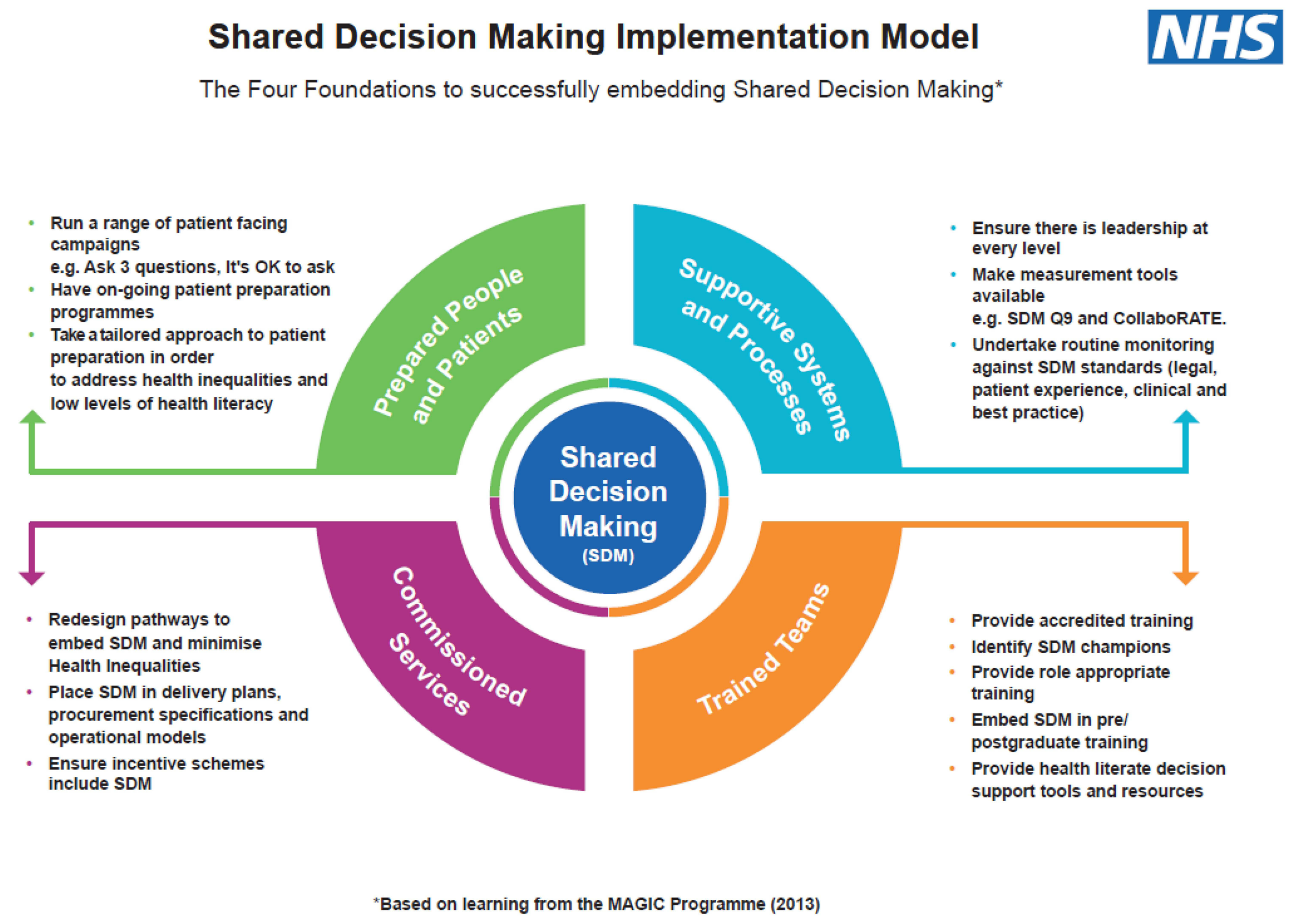
Healthcare providers should implement shared decision-making tools to facilitate discussions about patient preferences, values, and priorities (see Figure 1 for an example of a shared decision-making implementation model[45]). Information and decision aids, such as brochures, videos, audio resources, and online tools, can empower patients, caregivers, and families to actively participate in decision-making.[9]

Principle 6: Patients Need Access to Early Detection Services, Care, and Treatment Without Being Stigmatized

Access to early detection and timely care for HCC should not be hindered by stigma. However, stigma remains a significant barrier for many patients, often rooted in widespread misconceptions about the causes of HCC.

Many people associate HCC with lifestyle factors, such as heavy alcohol use, injection drug use, obesity or smoking.[46] These misconceptions can perpetuate negative stereotypes, making patients reluctant to seek help due to fear of judgment or social stigma. This can discourage individuals from undergoing necessary screening and surveillance for liver disease, delaying diagnosis and leading to higher mortality.[47,48]

Stigma not only impacts the psychological well-being of patients but also places a social and economic burden on their families. The fear of being judged can prevent patients from accessing essential healthcare services, ultimately contributing to poorer health outcomes. Storytelling and shared experiences can play a powerful role in reducing stigma and amplifying awareness. Programs like the Hepatitis B Foundation's #justB and B the Voice campaigns[49] have demonstrated the impact of sharing real-life stories from patients and caregivers. These initiatives humanize the experience of living with hepatitis B and liver disease, helping to break down misconceptions and promote understanding.



Shared Decision Making Implementation Model

The Four Foundations to successfully embedding Shared Decision Making*

- Run a range of patient facing campaigns e.g. Ask 3 questions, It's OK to ask
- Have on-going patient preparation programmes
- Take a tailored approach to patient preparation in order to address health inequalities and low levels of health literacy

- Ensure there is leadership at every level
- Make measurement tools available e.g. SDM Q9 and CollaboRATE.
- Undertake routine monitoring against SDM standards (legal, patient experience, clinical and best practice)

- Redesign pathways to embed SDM and minimise Health Inequalities
- Place SDM in delivery plans, procurement specifications and operational models
- Ensure incentive schemes include SDM

- Provide accredited training
- Identify SDM champions
- Provide role appropriate training
- Embed SDM in pre/ postgraduate training
- Provide health literate decision support tools and resources

*Based on learning from the MAGIC Programme (2013)

Figure 1 Example of a Shared Decision-Making Implementation Model – NHS England. Reprinted from NHS England. How to make shared decision making happen. 2025. Available from: https://www.england.nhs.uk/personalisedcare/shared-decision-making/how-to-make-shared-decision-making-happen/. Creative Commons.[45]

Reducing stigma requires sustained public education to correct false beliefs and emphasize that liver disease affects people of all backgrounds – not just those with certain behaviors. Normalizing routine screening and early surveillance for at-risk populations is key to reducing disparities and improving outcomes.

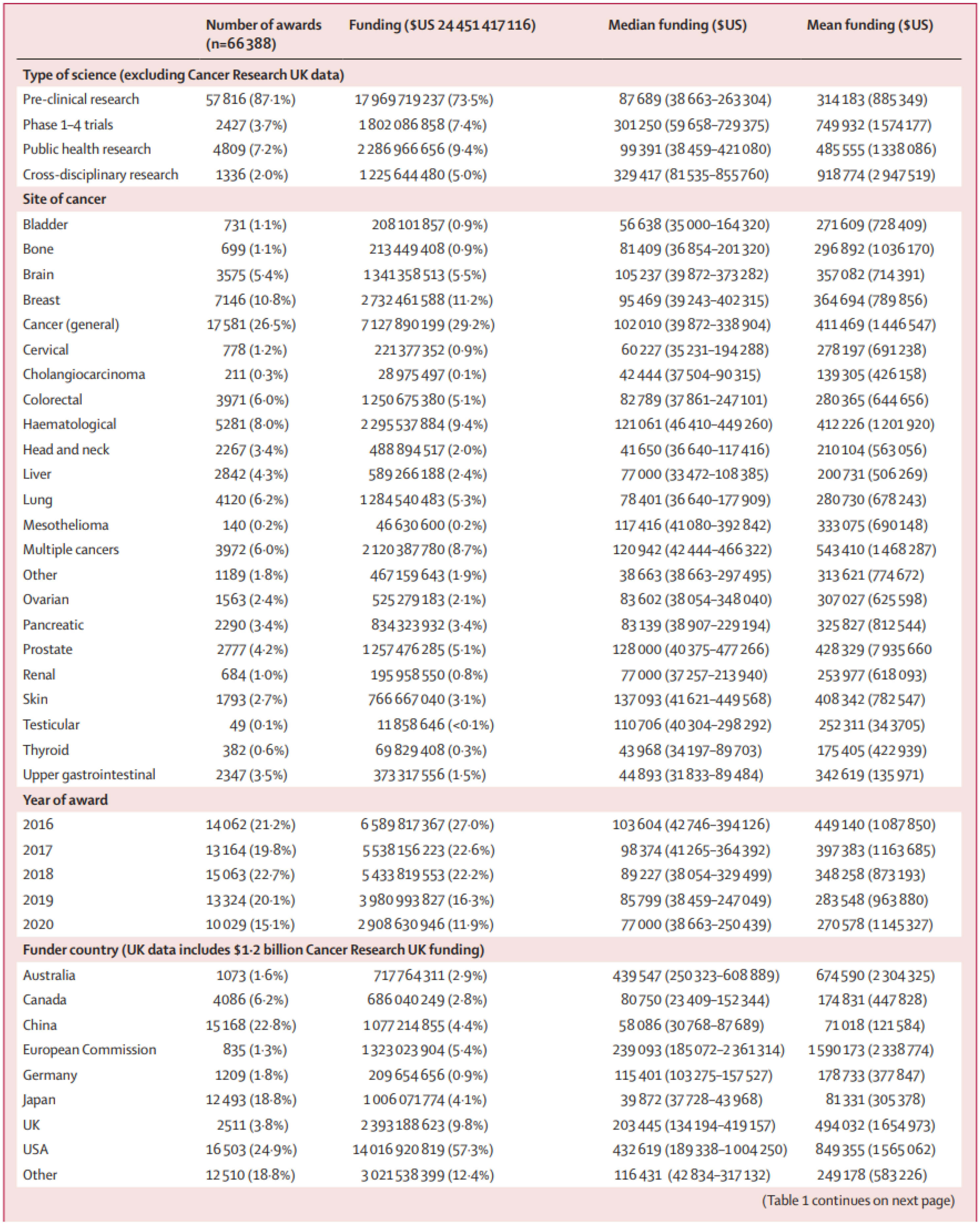
Emotional support is also critical. Patient advocacy groups, support networks, and survivor communities offer vital psychosocial resources that help individuals and families navigate the emotional impact of diagnosis, including depression and isolation.[50]

Comprehensive care must also address nutritional needs. Proper dietary guidance can slow disease progression, prevent complications, and improve quality of life.[51] Addressing the financial challenges faced by patients and caregivers is equally important, as economic strain can further compromise access to care and health outcomes.[52]

Principle 7: Patients Need a Commitment to Increased Funding and Further Research for HCC

HCC requires increased research funding and resources to drive advances in care. Despite being one of the deadliest cancers, HCC remains underfunded compared to other cancers (as shown in Figure 2),[53] which hampers progress in improving patient outcomes.

Current investment in HCC research is disproportionately low, especially in low- and middle-income countries, where the burden of liver cancer is highest. The majority of research funding for cancer biology is concentrated in high-income countries, yet regional differences in HCC suggest that findings from these studies may not be universally applicable.[53] Prioritizing HCC research on a global scale is essential to address disparities and ensure that advancements benefit all populations.



	Number of awards (n=66 388)	Funding ($US 24 451 417 116)	Median funding ($US)	Mean funding ($US)
Type of science (excluding Cancer Research UK data)				
Pre-clinical research	57 816 (87·1%)	17 969 719 237 (73·5%)	87 689 (38 663–263 304)	314 183 (885 349)
Phase 1–4 trials	2427 (3·7%)	1 802 086 858 (7·4%)	301 250 (59 658–729 375)	749 932 (1 574 177)
Public health research	4809 (7·2%)	2 286 966 656 (9·4%)	99 391 (38 459–421 080)	485 555 (1 338 086)
Cross-disciplinary research	1336 (2·0%)	1 225 644 480 (5·0%)	329 417 (81 535–855 760)	918 774 (2 947 519)
Site of cancer				
Bladder	731 (1·1%)	208 101 857 (0·9%)	56 638 (35 000–164 320)	271 609 (728 409)
Bone	699 (1·1%)	213 449 408 (0·9%)	81 409 (36 854–201 320)	296 892 (1 036 170)
Brain	3575 (5·4%)	1 341 358 513 (5·5%)	105 237 (39 872–373 282)	357 082 (714 391)
Breast	7146 (10·8%)	2 732 461 588 (11·2%)	95 469 (39 243–402 315)	364 694 (789 856)
Cancer (general)	17 581 (26·5%)	7 127 890 199 (29·2%)	102 010 (39 872–338 904)	411 469 (1 446 547)
Cervical	778 (1·2%)	221 377 352 (0·9%)	60 227 (35 231–194 288)	278 197 (691 238)
Cholangiocarcinoma	211 (0·3%)	28 975 497 (0·1%)	42 444 (37 504–90 315)	139 305 (426 158)
Colorectal	3971 (6·0%)	1 250 675 380 (5·1%)	82 789 (37 861–247 101)	280 365 (644 656)
Haematological	5281 (8·0%)	2 295 537 884 (9·4%)	121 061 (46 410–449 260)	412 226 (1 201 920)
Head and neck	2267 (3·4%)	488 894 517 (2·0%)	41 650 (36 640–117 416)	210 104 (563 056)
Liver	2842 (4·3%)	589 266 188 (2·4%)	77 000 (33 472–108 385)	200 731 (506 269)
Lung	4120 (6·2%)	1 284 540 483 (5·3%)	78 401 (36 640–177 909)	280 730 (678 243)
Mesothelioma	140 (0·2%)	46 630 600 (0·2%)	117 416 (41 080–392 842)	333 075 (690 148)
Multiple cancers	3972 (6·0%)	2 120 387 780 (8·7%)	120 942 (42 444–466 322)	543 410 (1 468 287)
Other	1189 (1·8%)	467 159 643 (1·9%)	38 663 (38 663–297 495)	313 621 (774 672)
Ovarian	1563 (2·4%)	525 279 183 (2·1%)	83 602 (38 054–348 040)	307 027 (625 598)
Pancreatic	2290 (3·4%)	834 323 932 (3·4%)	83 139 (38 907–229 194)	325 827 (812 544)
Prostate	2777 (4·2%)	1 257 476 285 (5·1%)	128 000 (40 375–477 266)	428 329 (7 935 660
Renal	684 (1·0%)	195 958 550 (0·8%)	77 000 (37 257–213 940)	253 977 (618 093)
Skin	1793 (2·7%)	766 667 040 (3·1%)	137 093 (41 621–449 568)	408 342 (782 547)
Testicular	49 (0·1%)	11 858 646 (<0·1%)	110 706 (40 304–298 292)	252 311 (34 3705)
Thyroid	382 (0·6%)	69 829 408 (0·3%)	43 968 (34 197–89 703)	175 405 (422 939)
Upper gastrointestinal	2347 (3·5%)	373 317 556 (1·5%)	44 893 (31 833–89 484)	342 619 (135 971)
Year of award				
2016	14 062 (21·2%)	6 589 817 367 (27·0%)	103 604 (42 746–394 126)	449 140 (1 087 850)
2017	13 164 (19·8%)	5 538 156 223 (22·6%)	98 374 (41 265–364 392)	397 383 (1 163 685)
2018	15 063 (22·7%)	5 433 819 553 (22·2%)	89 227 (38 054–329 499)	348 258 (873 193)
2019	13 324 (20·1%)	3 980 993 827 (16·3%)	85 799 (38 459–247 049)	283 548 (963 880)
2020	10 029 (15·1%)	2 908 630 946 (11·9%)	77 000 (38 663–250 439)	270 578 (1 145 327)
Funder country (UK data includes $1·2 billion Cancer Research UK funding)				
Australia	1073 (1·6%)	717 764 311 (2·9%)	439 547 (250 323–608 889)	674 590 (2 304 325)
Canada	4086 (6·2%)	686 040 249 (2·8%)	80 750 (23 409–152 344)	174 831 (447 828)
China	15 168 (22·8%)	1 077 214 855 (4·4%)	58 086 (30 768–87 689)	71 018 (121 584)
European Commission	835 (1·3%)	1 323 023 904 (5·4%)	239 093 (185 072–2 361 314)	1 590 173 (2 338 774)
Germany	1209 (1·8%)	209 654 656 (0·9%)	115 401 (103 275–157 527)	178 733 (377 847)
Japan	12 493 (18·8%)	1 006 071 774 (4·1%)	39 872 (37 728–43 968)	81 331 (305 378)
UK	2511 (3·8%)	2 393 188 623 (9·8%)	203 445 (134 194–419 157)	494 032 (1 654 973)
USA	16 503 (24·9%)	14 016 920 819 (57·3%)	432 619 (189 338–1 004 250)	849 355 (1 565 062)
Other	12 510 (18·8%)	3 021 538 399 (12·4%)	116 431 (42 834–317 132)	249 178 (583 226)

(Table 1 continues on next page)

Figure 2 Awards for cancer research between Jan 1, 2016 and Dec 31, 2020. Adapted from McIntosh SA, Alam F, Adams L, et al. Global funding for cancer research between 2016 and 2020: a content analysis of public and philanthropic investments. *Lancet Oncol*. 2023;24(6):636–645. Creative Commons.[53]

https://doi.org/10.2147/JHC.S526170

Addressing gaps in diagnostics, treatments and data collection is crucial to advancing care for HCC. Currently, there is no consensus on the most effective screening methods for early detection of HCC. This gap highlights the urgent need for additional research to validate novel biomarkers, genetic tests and advanced imaging techniques that could improve early diagnosis. Early detection remains key to optimizing patient outcomes, as a significant proportion of HCC cases are diagnosed at advanced stages, when curative options are limited. In parallel, research into targeted therapies, particularly systemic and immune-based treatments, is progressing; however, there remains insufficient data linking specific molecular profiles to the most effective therapies. This limitation underscores the need for personalized approaches in HCC treatment, where care can be tailored based on the genetic and molecular characteristics of a patient's tumor. To achieve this, more studies are required to delineate how distinct molecular signatures influence treatment responses, allowing clinicians to select the most appropriate therapies for each patient.

Moreover, enhancing data collection through comprehensive national and international registries is essential to improving our understanding of treatment outcomes. Currently, there is limited data on how various clinical factors, such as underlying liver disease etiology – whether viral hepatitis or MASLD – affect responses to HCC treatments. Systematic collection of this information will not only inform evidence-based guidelines but also support the development of tailored management strategies. Investing in robust data infrastructure will enable a deeper analysis of real-world patient outcomes, therefore refining therapeutic approaches and improving long-term survival rates for HCC patients.[54]

Limitations

The development of this patient charter was shaped by a collaborative process involving clinical experts, patient advocates, and stakeholders, including industry representatives. While this inclusive approach enriched the content and ensured a broad perspective, it also introduced certain limitations. Although every effort was made to maintain the independence and integrity of the charter's content, the potential for bias arising from industry involvement cannot be entirely excluded. Additionally, while the charter reflects current best practices and expert consensus, it may not capture the full diversity of experiences across all regions, healthcare systems, or patient populations. Further validation through wider public and professional engagement is encouraged to enhance the charter's applicability and inclusivity.

Conclusion

HCC represents a major burden for millions of people worldwide, significantly affecting their quality of life, mental health, and overall well-being. It also places considerable strain on healthcare systems, with late-stage diagnoses and inconsistent access to effective treatments exacerbating the issue.

The principles and recommendations outlined in this paper highlight the essential components of quality care for people living with HCC. We urge healthcare providers, policymakers, and health systems globally to adopt and implement comprehensive strategies that prioritize HCC prevention, early diagnosis, multidisciplinary care, personalized treatment, and equitable access to therapies. In doing so, we can ensure that the latest advancements in HCC care reach those who need them most, ultimately improving outcomes and reducing the global impact of this disease.

Data Sharing Statement

Data sharing is not applicable as no datasets generated and/or analyzed for this study.

Ethics Approval and Informed Consent

Not applicable for this study. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

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Disclosure

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References

1. Rumgay H, Ferlay J, de Martel C, et al. Global, regional and national burden of primary liver cancer by subtype. *Eur J Cancer*. 2022;161:108–118. doi:10.1016/j.ejca.2021.11.023. Epub 2021 Dec 20. PMID: 34942552.
2. World Cancer Research Fund International. Liver cancer statistics. Available from: https://www.wcrf.org/cancer-trends/liver-cancer-statistics/#:~:text=Latest%20liver%20cancer%20data,ASR%20%3D%20age%2Dstandardised%20rates. Accessed October 5, 2024.
3. International Agency for Research on Cancer World Health Organisation. Cancer Today – datavis. Available from: https://gco.iarc.fr/today/en/dataviz/pie?mode=cancer&cancers=11&group_populations=1&types=1&sort_by=value1. Accessed Aug 08, 2025.
4. Fa A, Danos DM, Maniscalco L, et al. Is There Really a Difference in Outcomes between Men and Women with Hepatocellular Cancer? *Cancers*. 2023;15(11):2892. doi:10.3390/cancers15112892. PMID: 37296854; PMCID: PMC10251901.
5. Asafo-Agyei KO, Samant H. Hepatocellular Carcinoma. In: *StatPearls*. Treasure Island (FL): StatPearls Publishing; 2024. Available from https://www.ncbi.nlm.nih.gov/books/NphBK559177/.
6. Mentha N, Clément S, Negro F, Alfaiate D. A review on hepatitis D: from virology to new therapies. *J Adv Res*. 2019;17:3–15. doi:10.1016/j.jare.2019.03.009
7. Tojjari A, Saeed A, Singh M, Cavalcante L, Sahin IH, Saeed A. A comprehensive review on cancer vaccines and vaccine strategies in hepatocellular carcinoma. *Vaccines*. 2023;11(8):1357. doi:10.3390/vaccines11081357
8. Yang C, Zhang H, Zhang L, et al. Evolving therapeutic landscape of advanced hepatocellular carcinoma. *Nat Rev Gastroenterol Hepatol*. 2023;20(4):203–222. doi:10.1038/s41575-022-00704-9
9. Gordan J, Kennedy EB, Abou-Alfa GK, et al. Systemic Therapy for Advanced Hepatocellular Carcinoma: ASCO Guideline Update. *J Clin Oncol*. 2024;42(15):1830–1850. doi:10.1200/JCO.23.02745
10. Liao W, Coupland CAC, Innes H, et al. 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;59:101969. doi:10.1016/j.eclinm.2023.101969
11. Kim E, Viatour P. Hepatocellular carcinoma: old friends and new tricks. *Exp Mol Med*. 2020;52(12):1898–1907. doi:10.1038/s12276-020-00527-1
12. El-Serag HB. Epidemiology of viral hepatitis and hepatocellular carcinoma. *Gastroenterology*. 2012;142(6):1264–1273.e1. doi:10.1053/j.gastro.2011.12.061. PMID: 22537432; PMCID: PMC3338949.
13. Park JW, Chen M, Colombo M, et al. Global patterns of hepatocellular carcinoma management from diagnosis to death: the BRIDGE Study. *Liver Int*. 2015;35(9):2155–2166. doi:10.1111/liv.12818
14. Sherman M. How to improve HCC surveillance outcomes. *JHEP Rep*. 2019;1(6):460–467. doi:10.1016/j.jhepr.2019.10.007
15. Rich NE, Hester C, Odewole M, et al. Racial and Ethnic Differences in Presentation and Outcomes of Hepatocellular Carcinoma. *Clin Gastroenterol Hepatol*. 2019;17(3):551–559e1. doi:10.1016/j.cgh.2018.05.039
16. Kim NJ, Cravero A, VoPham T. Addressing racial and ethnic disparities in US liver cancer care. *Hepatol Commun*. 2023;7(7):e00190. doi:10.1097/HC9.0000000000000190
17. International Liver Cancer Movement. The INTERNATIONAL LIVER CANCER NETWORK asks for reinforced efforts to improve patient outcomes: PREVENTION, EARLY DETECTION and ACCESS TO CARE. 2021. Available from: https://ilcm.global/files/ilcm_layout/RESOURCES/ILCN%20White%20Paper_2021.pdf. Accessed June 01, 2025.
18. European Association for the Study of the Liver. Electronic address: easloffice@easloffice.eu; European Association for the Study of the Liver. EASL Clinical Practice Guidelines: management of hepatocellular carcinoma, *J Hepatol*. 2018;69(1):182–236. doi:10.1016/j.jhep.2018.03.019. Epub 2018 Apr 5. Erratum in: J Hepatol. 2019;70(4):817. doi: 10.1016/j.jhep.2019.01.020. PMID: 29628281
19. Singal AG, Llovet JM, Yarchoan M, et al. AASLD Practice Guidance on prevention, diagnosis, and treatment of hepatocellular carcinoma. *Hepatology*. 2023;78(6):1922–1965. doi:10.1097/HEP.0000000000000466
20. Shiina S, Gani RA, Yokosuka O, et al. APASL practical recommendations for the management of hepatocellular carcinoma in the era of COVID-19. *Hepatol Int*. 2020;14(6):920–929. doi:10.1007/s12072-020-10103-4. Epub 2020 Nov 11. PMID: 33174159; PMCID: PMC7655459.
21. Arab JP, Dirchwolf M, Álvares-da-silva MR, et al. Latin American Association for the study of the liver (ALEH) practice guidance for the diagnosis and treatment of non-alcoholic fatty liver disease. *Ann Hepatol*. 2020;19(6):674–690. doi:10.1016/j.aohep.2020.09.006. Epub 2020 Oct 5. PMID: 33031970.
22. Acharya SK, Bopanna S. Hepatocellular Carcinoma Screening and Nonalcoholic Fatty Liver Disease: how is it Different? *J Clin Experiment Hepatol*. 2020;10(5):518–524. doi:10.1016/j.jceh.2020.04.004
23. McMahon B, Cohen C, Brown Jr RS, et al. Opportunities to address gaps in early detection and improve outcomes of liver cancer. *JNCI Cancer Spectr*. 2023;7(3). doi:10.1093/jncics/pkad034
24. Digestive Cancers Europe. Insights and Key Findings: hepatocellular Carcinoma Prevention and Diagnosis Mapping Project, 2024. Available from: https://digestivecancers.eu/wp-content/uploads/2024/10/executive-summary-lcam2024.pdf. Accessed Aug 05, 2025.

25. Singal AG, Lok AS, Feng Z, Kanwal F, Parikh ND. Conceptual Model for the Hepatocellular Carcinoma Screening Continuum: current Status and Research Agenda. *Clin Gastroenterol Hepatol*. 2022;20(1):9–18. doi:10.1016/j.cgh.2020.09.036
26. Qurashi M, Sharma R, et al. Improving hepatocellular carcinoma surveillance in the United Kingdom: challenges and solutions Qurashi, Maria et al. *Lancet Regional Health*. 2024;43:100963. doi:10.1016/j.lanepe.2024.100963
27. Kinsey E, Lee HM. Management of Hepatocellular Carcinoma in 2024: the Multidisciplinary Paradigm in an Evolving Treatment Landscape. *Cancers*. 2024;16(3):666. doi:10.3390/cancers16030666
28. Zhu H, Patel MS, Gopal P, Parikh ND, Yopp AC, Singal AG. Multidisciplinary care for patients with HCC: a systematic review and meta-analysis. *Hepatol Commun*. 2023;7(5):1.
29. Reig M, Forner A, Rimola J, et al. BCLC strategy for prognosis prediction and treatment recommendation: the 2022 update. *J Hepatol*. 2022;76 (3):681–693. doi:10.1016/j.jhep.2021.11.018
30. Cho Y, Kim BH, Park JW. Overview of Asian clinical practice guidelines for the management of hepatocellular carcinoma: an Asian perspective comparison. *Clin Mol Hepatol*. 2023;29(2):252–262. doi:10.3350/cmh.2023.0099. Epub 2023 Mar 10. PMID: 36907570; PMCID: PMC10121305.
31. Sinn DH, Choi G-S, Park HC, et al. Multidisciplinary approach is associated with improved survival of hepatocellular carcinoma patients. *PLoS One*. 2019;14(1):e0210730. doi:10.1371/journal.pone.0210730
32. Naugler WE, Alsina AE, Frenette CT, et al. Building the multidisciplinary team for management of patients with hepatocellular carcinoma. *Clin Gastroenterol Hepatol*. 2015;13(5):827–835. doi:10.1016/j.cgh.2014.03.038
33. Harrington C. Composition of An Ideal Medical Care Team. *Dela J Public Health*. 2022;8(5):150–153. doi:10.32481/djph.2022.12.033. PMID: 36751608; PMCID: PMC9894047.
34. Association of Community Cancer Centres. Multidisciplinary Hepatocellular Carcinoma Care. 2021. Available from: https://www.accc-cancer.org/docs/projects/hcc/hcc-pub_web.pdf?sfvrsn=fdd53564_0. Accessed July 01, 2024.
35. NHS. Long Term Plan. 2019. Available from: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf. Accessed July 01, 2024.
36. Loren AW, et al. Fertility Preservation in People With Cancer: ASCO Guideline Clinical Insights. *JCO Oncol Pract*. 2025;2025:1. doi:10.1200/OP-25-00223
37. Elwyn G, Frosch D, Thomson R, et al. Shared Decision Making: a Model for Clinical Practice. *J GEN INTERN MED*. 2012;27(10):1361–1367. doi:10.1007/s11606-012-2077-6
38. Johnson L, Kirk H, Clark B, et al. Improving personalised care, through the development of a service evaluation tool to assess, understand and monitor delivery. *BMJ Open Qual*. 2023;12(3):e002324. doi:10.1136/bmjoq-2023-002324
39. Sun H, Yang H, Mao Y. Personalized treatment for hepatocellular carcinoma in the era of targeted medicine and bioengineering. *Front Pharmacol*. 2023;14:1150151. doi:10.3389/fphar.2023.1150151. PMID: 37214451; PMCID: PMC10198383.
40. NICE. Home care: delivering personal care and practical support to older people living in their own homes. 2015. Available from: https://www.nice.org.uk/guidance/ng21/chapter/recommendations. Accessed July 01, 2024.
41. Lau G, Obi S, Zhou J, et al. APASL clinical practice guidelines on systemic therapy for hepatocellular carcinoma-2024. *Hepatol Int*. 2024;18 (6):1661–1683. doi:10.1007/s12072-024-10732-z
42. ClinicalTrials.gov. Sharing Decision-making Program for HCC Patients Treatment Decisions. 2021. Available from: https://clinicaltrials.gov/study/NCT03926039. Accessed Jul 04, 2024.
43. European Cancer Organisation. Shared Decision Making. Available from: https://www.europeancancer.org/content/the-code-shared-decision-making.html#:~:text=A%20treatment%20preference%20may%20be,should%20improve%20QoL%20and%20survival. Accessed Aug 05, 2025.
44. Gill J, Baiceanu A, Clark PJ, et al. Insights Into the Hepatocellular Carcinoma Patient Journey: results of the First Global Quality of Life Survey. *Future Oncol*. 2018;14(17):1701–1710. doi:10.2217/fon-2017-0715
45. NHS England. How to make shared decision making happen. 2025. Available from: https://www.england.nhs.uk/personalisedcare/shared-decision-making/how-to-make-shared-decision-making-happen/. Accessed May 01, 2025.
46. Cancer Support Community. 3 Ways to Shatter the Stigma of Liver Cancer & Find Healing. 2023. Available from: https://www.cancersupportcommunity.org/blog/shatter-stigma-liver-cancer-find-healing. Accessed July 01, 2024.
47. Liver Cancer UK. New data shows how liver cancer hits vulnerable groups hardest. 2024. Available from: https://livercanceruk.org/news/new-data-shows-how-liver-cancer-hits-vulnerable-groups-hardest/. Accessed July 01, 2024.
48. Health Awareness. How stigma can delay liver disease diagnosis. 2021. Available from: https://www.healthawareness.co.uk/liver/how-stigma-can-delay-liver-disease-diagnosis/. Accessed July 01, 2024.
49. Hepatitis B Foundation. Storytelling: the lived experience of having hepatitis B. 2024. Available from: https://www.hepb.org/research-and-programs/patient-story-telling-project/. Accessed December 01, 2024.
50. Canadian Cancer Liver Network. Liver Cancer Stigma. Available from: https://survivornet.ca/hcc-portal/liver-cancer-primary/living-well-primary-liver-cancer/liver-cancer-stigma/. Accessed July 01, 2024.
51. Jamioł-Milc D, Gudan A, Kaźmierczak-Siedlecka K, et al. Nutritional Support for Liver Diseases. *Nutrients*. 2023;15(16):3640. doi:10.3390/nu15163640
52. Ufere NN, Lai JC, Lai JC, Serper M, Serper M. Financial burden in adults with chronic liver disease: a scoping review. *Liver Transpl*. 2022;28 (12):1920–1935. doi:10.1002/lt.26514
53. McIntosh SA, Alam F, Adams L, et al. Global funding for cancer research between 2016 and 2020: a content analysis of public and philanthropic investments. *Lancet Oncol*. 2023;24(6):636–645. doi:10.1016/S1470-2045(23)00182-1
54. Singal AG, Kudo M, Bruix J. Breakthroughs in hepatocellular carcinoma therapies. *Clin Gastroenterol Hepatol*. 2023;21(8):2135–2149. doi:10.1016/j.cgh.2023.01.039