

A Summary of the HCC-CARE Symposium: Collaborative Approaches to Reaching Equity in Hepatocellular Carcinoma in Boston by 2030

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Abstract: Hepatocellular carcinoma (HCC) is a leading cause of cancer mortality in the United States. Disparities in HCC incidence and mortality are amplified in Boston, Massachusetts, which has 42% higher HCC mortality than the nation. HCC-CARE was a one-day symposium that aimed to identify goals and strategies necessary to eliminate HCC disparities in the Greater Boston area by 2030. Sixty-six local and state stakeholders attended the symposium, including HCC clinical experts (eg, medical oncologists) and primary care clinicians representing all seven of Boston's major cancer centers, ancillary staff members (eg, social workers) and state and local government agencies. The symposium included introductory sessions on HCC disparities, conceptual approaches to addressing disparities, and perspectives of local stakeholders on HCC disparities, followed by two interactive workshops where nine groups brainstormed and voted on goals, then developed preliminary action plans. Symposium participants identified four priority goals and developed associated action plans to eliminate HCC disparities by 2030: 1) improving HCC screening rates to enable early detection, 2) employing community engagement and outreach to communities at high risk of HCC, 3) developing a multi-institutional HCC registry to inform care delivery improvements, and 4) connecting patients with HCC to support services to address common barriers to care. A fifth priority around addressing disparities in HCC treatment emerged from post-symposium feedback. HCC-CARE established a knowledge base and raised the saliency of HCC disparities among participants, created a multi-institutional consortium of individuals committed to addressing HCC disparities, and leveraged the wide-ranging expertise of the participants to identify key goals and strategies for achieving equity in HCC outcomes by 2030. These strategies require further development and implementation through multi-institutional committees established after the symposium for each priority area. The Symposium represented a key first step in launching coordinated efforts to reduce HCC disparities that other cities may emulate.

Keywords: hepatocellular carcinoma, health equity

Introduction

In 2016, hepatocellular carcinoma (HCC) was the sixth leading cause of cancer deaths in the United States (US) but is expected to rise to the third leading cause by 2040.¹ The US has significant disparities in HCC incidence and survival. Asian and Black individuals have an HCC incidence nearly double that of White individuals (8.1, 8.2 and 4.3 diagnoses per 100,000 person-years, respectively).² Among SEER-Medicare populations, Asian patients with HCC have the best median survival of 14.2 months, compared to 9.5 and 5.6 months for White and Black patients, respectively (C Manz, Dana-Farber Cancer Institute, personal communication, June, 2025). HCC disparities are amplified in Boston,

Massachusetts, which have HCC mortality rates that are 42% higher than the rest of the state and the country (9.2 for Boston vs 6.5 for both Massachusetts and nationally, per 100,000).³ In Boston, Asian men have double the HCC incidence (33 vs 17 cases per 100,000) with similar mortality (13 per 100,000 for both) compared to White men, while Black men have similar incidence (17 per 100,000 for both) but 38% higher mortality (18 vs 13 per 100,000 men).³

Disparities in HCC incidence are related to disparities in underlying causes of HCC such as alcohol-related liver disease, viral hepatitis and metabolic dysfunction-associated steatotic liver disease (MASLD), as well as disparities in treatment of these conditions.^{4–6} Moreover, HCC disproportionately affects key patient populations that are already vulnerable to poor health outcomes, such as immigrant communities with limited English proficiency as well as those experiencing homelessness or incarceration.^{7,8} After an HCC diagnosis, survival disparities may be driven by several factors, including differential access to gastroenterology care, HCC screening and receipt of HCC treatment (C Manz, Dana-Farber Cancer Institute, personal communication, June, 2025).^{9,10} While targeted interventions have successfully improved treatment and survival for cancers such as colorectal and lung, there are few, if any, interventions that have improved HCC disparities.^{11–15} Given that many contributors to HCC disparities may occur upstream of a cancer diagnosis, collaborative approaches across institutions and clinical roles are necessary to improve HCC outcomes equitably.

HCC care in the Boston region is primarily delivered at seven academically affiliated healthcare institutions. Historically, there have not been concerted efforts to advance HCC care across institutions across the Boston region. The HCC-CARE (Collaborative Approaches to Reaching Equity in Hepatocellular Carcinoma) Symposium was organized to convene stakeholders across clinical roles and institutions in the Boston area to identify goals and strategies to eliminate HCC disparities in our community by 2030.

Symposium Design

HCC-CARE was a one-day symposium that took place in Boston on October 22, 2024, and convened 66 participants from across the Boston region. To ensure the inclusion of perspectives across clinical roles, participants were invited using snowball sampling of gastroenterologists, transplant hepatologists, surgeons, diagnostic radiologists, interventional radiologists, medical oncologists, radiation oncologists, infectious disease specialists, and primary care providers from each of Boston's seven main healthcare institutions; ancillary staff such as patient navigators; and other key stakeholders including Federally Qualified Health Centers, public health officials and payors from across the state ([Supplemental Figure 1](#)). The symposium aimed to bridge the gap from data to action on HCC disparities. By convening individuals across institutions and role groups, HCC-CARE sought to catalyze the development of a collaborative, regional strategy to achieve equity in HCC diagnosis, treatment and survival by 2030.

Informational Sessions to Frame the Issue and Policy Environment

Introductory sessions aimed to establish a common understanding of care standards for HCC screening and treatment and to identify survival disparities and possible drivers of these disparities. The published literature describing HCC treatment and survival disparities in the US was summarized using race/ethnicity as a lens, though there was widespread recognition that other characteristics such as preferred language, health literacy, socioeconomic status, and geography also contribute to HCC disparities. Compared to White or Asian patients, studies showed lower rates of screening, gastroenterology care, locoregional therapy, and curative-intent treatment, as well as worse survival for Black patients with HCC.^{9,10,16} The contribution of health-related social needs to disparities in these outcomes was also illustrated.¹⁶

To help participants systematically think about cancer disparities, participants were introduced to the National Cancer Institute (NCI) conceptual model illustrating how HCC disparities arise across the care continuum, the National Institute of Minority Health and Health Disparities research framework on health disparities, and HCC-specific conceptual models illustrating where disparities may propagate across levels of influence.^{17–19} Three case studies were then highlighted as successful multilevel interventions that incorporated these conceptual models: the Delaware Cancer Consortium's work that reduced racial disparities in colonoscopies and colorectal cancer mortality in Delaware; the ACCURE project that eliminated racial disparities in receipt of and time to treatment for patients with lung cancer at cancer centers in Pennsylvania, North Carolina and South Carolina; and the TRIP partnership that implemented a city-wide navigation

and registry program to address breast cancer disparities in Boston after convening stakeholders in a meeting similar to HCC-CARE.^{11–15,20}

Finally, presenters illustrated how concerted efforts to address care disparities can be successful even in the most vulnerable of patient populations, using a program to treat Hepatitis C in Boston's homeless patients as an example. Additional presenters summarized the policy environment in Boston and Massachusetts, highlighting city and state efforts to improve cancer disparities, including a recently announced plan to eliminate Hepatitis C.²¹

Local Healthcare Institution Perspectives on HCC Disparities

The next session highlighted the perspectives of local healthcare institutions on HCC disparities. Prior to the symposium, representatives from each of Boston's seven main healthcare institutions along with an association of community primary care clinics in Massachusetts were invited to prepare brief remarks summarizing their institutional strengths, challenges, and opportunities for collaboration. Institutions were heterogeneous with respect to the sociodemographic makeup of their patient populations, treatment offerings including the availability of liver transplantation, and research infrastructure, but several best practices emerged from their presentations.

Many institutions reported having a dedicated multidisciplinary HCC clinic in which patients with newly diagnosed HCC could be quickly triaged and evaluated by all relevant medical subspecialties including transplant hepatology, transplant surgery or surgical oncology, interventional radiology, medical oncology, and radiation oncology, often within the same clinic visit. Patient navigation was highlighted as another effective strategy for engaging patients in their HCC care and for systematically screening for and addressing health-related social needs such as transportation barriers and difficulty paying medical bills. Some institutions shared their efforts to coordinate upstream services in the HCC care continuum, such as treating HCC risk factors, systematically screening patients at high risk for HCC, and linking patients newly diagnosed with HCC with cancer care. No single institution reported following all these best practices, so most of the discussion emphasized the importance of partnering with other local institutions to leverage each other's respective strengths.

There were several challenges identified across all institutions. Institutional presenters highlighted the need to address limited health literacy, language barriers, and financial constraints that are common among patients with HCC, which can make serial screening, therapeutic interventions, and longitudinal follow-up difficult. Care coordination across multiple medical subspecialties and healthcare institutions was also identified as another challenge. Difficulty of ascertaining screening rates was identified as a key barrier to improving screening, as only two institutions were able to provide baseline screening rates (ranging from 44 to 60%). Finally, collaborative research efforts were highlighted as an important but underutilized mechanism to conduct both observational and prospective studies to improve screening, treatment, and care delivery for patients with HCC.

Workshop I: Identifying Goals to Reduce HCC Disparities

The objective of the first workshop was to identify priority goals that are necessary for eliminating HCC disparities in Boston by 2030. Organizers assigned participants to one of the nine working groups to ensure that each group had a relatively even representation of role groups and institutions. Each group brainstormed concrete goals to eliminate HCC disparities over 5 years using S.M.A.R.T. (specific, measurable, achievable, relevant, and time-bound) goal setting, a commonly used framework for identifying actionable goals.²² To prompt brainstorming of goals across the care continuum, we provided a diagram of the NCI's conceptual model for multilevel interventions.¹⁷ Each group selected the three goals they felt were most important to reducing HCC disparities, wrote these goals on flip charts and briefly presented their goals in a report-back session, resulting in 26 goals (Figure 1, Supplemental Table 1). Facilitated discussion highlighted goals that were thematically linked (eg, goals related to HCC screening).

Participants were then given color-coded stickers based on their role groups (eg, gastroenterology/hepatology, medical oncology, etc.), which they used to vote for the three goals they felt were most important to eliminating HCC disparities by 2030. Organizers aggregated votes across themes in real-time based on the facilitated discussion during the workshop, with four overarching themes emerging as having the strongest support (Figure 1):

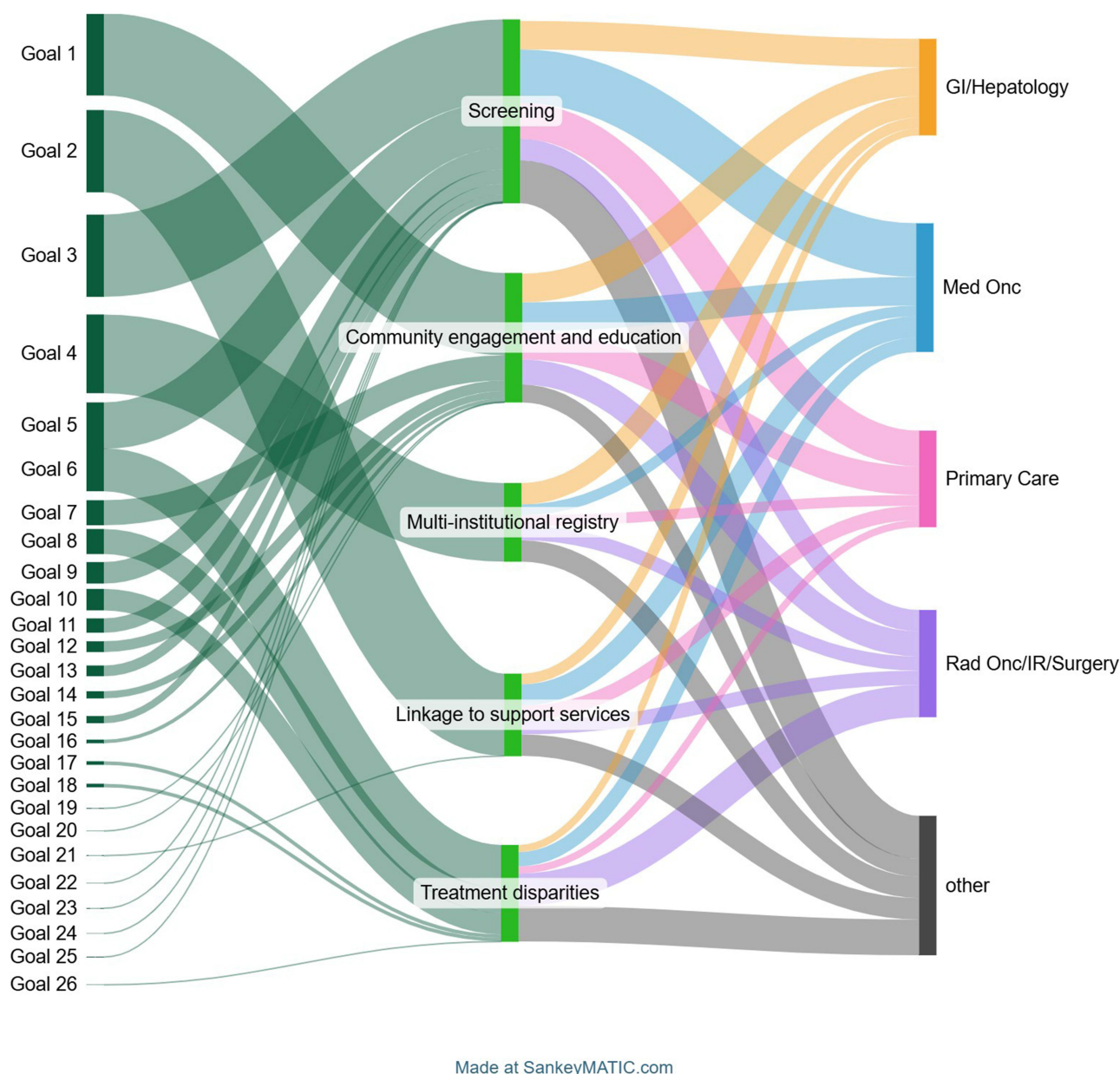


Figure 1 Goals and voting patterns. On the left, goals are listed in order of highest vote total and converge into themes in the center. See [Supplemental Table 1](#) for a description of each goal. On the right, votes by role group converge into the themes in the center.

Abbreviations: GI, gastroenterology; IR, interventional radiology; Med Onc, medical oncology; Rad Onc, radiation oncology.

1. Improve HCC screening rates to enable early detection, which may enable equitable treatment, particularly of curative-intent treatments.
2. Develop relationships with communities at high risk of HCC to facilitate patient education on HCC prevention and screening through community engagement and outreach.
3. Develop a multi-institutional HCC registry to enable timely referrals to specialty care and data-informed care delivery improvements.
4. Connect patients with and at risk for HCC to support services to address common practical and social barriers to care.

The goals shared broad support across all role groups (Figure 1). A fifth theme – reducing treatment disparities – emerged out of post-symposium review of goals and vote tallies, as well as participant feedback.

Workshop 2: Developing Strategies for the Top Four Themes

Participants split into their original working groups and selected one of the four themes to devise an initial action plan. In the report-back session, one group per theme proposed their action plan and other participants discussed and modified the plans. Theme-specific action plans are summarized in the Table 1. To improve HCC screening rates, participants highlighted the importance of improving the identification of patients who are eligible for HCC screening, raising awareness about HCC screening guidelines among clinicians, and ensuring that patients with positive screening were linked with HCC care in a timely manner. Community engagement and outreach included the need to build relationships with communities at high risk for HCC and leverage those connections to raise awareness about HCC risk factors and screening. Developing a multi-institutional HCC registry would require clear identification of registry objectives, scope, and collaborating institutions followed by construction of the registry infrastructure itself. To better connect patients to support services, participants emphasized the importance of systematically identifying health-related social needs among patients with and at risk for HCC and linking those patients with resources and organizations that could address their unmet needs. All plans emphasized collaborative approaches to addressing drivers of disparities that occur within, between and outside of healthcare institutions. Participants noted that the action plans were just a starting point, and more in-depth discussion and wider engagement was necessary to develop comprehensive strategies to address each theme.

Table 1 Themes, Action Plans, and Levels of Intervention

Theme	Action Items	Level of Intervention
Improve HCC screening rates	Improve the identification of patients who are eligible for HCC screening	
	Assess HCC risk factors such as alcohol and other substance use on patient intake questionnaires	Providers, health care organizations
	Flag radiographic findings of cirrhosis to explicitly identify patients as possibly benefitting from HCC screening	Health care organizations
	Develop clinical decision support tools to facilitate serial screening over time	Health care organizations
	Raise awareness about HCC screening among clinicians	
	Provide education on HCC screening guidelines and resources among clinicians who are upstream in the HCC care continuum (eg, primary care providers, gastroenterologists, infectious disease specialists)	Providers, health care organizations
	Facilitate statewide tracking and reporting on HCC screening rates (akin to ongoing efforts for colorectal and breast cancers)	Local/state-level policy
	Ensure timely linkage to HCC care for patients with positive screening	
	Assemble an “HCC response team” comprised of patient navigators and clinicians to ensure that patients with newly diagnosed HCC are evaluated and treated in a timely manner	Local/state-level policy
	Facilitate insurance coverage determinations for subspecialist referrals	National policy
Community engagement and outreach	Build relationships with communities at high risk for HCC	
	Partner with community organizations such as cultural groups, religious institutions, homeless shelters, Alcoholics/Narcotics Anonymous, and syringe exchanges	Local/state-level policy, health care organizations
	Identify community-based champions who can serve as liaisons between the community and healthcare institutions to ensure that patients are linked with the appropriate HCC care	Local/state-level policy, health care organizations
	Raise awareness about HCC risk factors and screening in the community	
	Develop patient-facing educational materials focused on HCC risk factors, screening indications, and screening locations in the Boston area	Individual patients, local/state-level policy
	Advertise in public spaces such as in the public transit system, local YMCAs, and community events	Local/state-level policy
	Be thoughtful about the use of social media campaigns, particularly among populations that may not have access to mobile devices	Local/state-level policy

(Continued)

Table 1 (Continued).

Theme	Action Items	Level of Intervention
Develop a multi-institutional HCC registry	Determine clear objectives and scope of a multi-institutional HCC registry	
	Enhance clinical care by linking patients to transplant centers and clinical trial opportunities	Local/state-level policy
	Identify patterns of HCC care delivery, including any disparities in care	Health care organizations
	Evaluate clinical outcomes in a large, diverse cohort of patients	Local/state-level policy, health care organizations
	Build a centralized registry	
	Identify common data elements and process measures necessary to achieve above objectives	Health care organizations
	Build informatics infrastructure	Health care organizations
	Ensure adequate privacy and security protections for participating patients and institutions	Health care organizations
	Identify collaborating institutions	
	Include institutions beyond Boston's major cancer centers and affiliated primary care networks to ensure adequate patient representation throughout the city	Local/state-level policy
Connect patients to support services	Improve the identification of health-related social needs among patients with and at risk for HCC	
	Conduct systematic assessments to identify unmet needs such as transportation needs and food insecurity	Providers, health care organizations
	Leverage patient navigation to help identify and overcome barriers to care	Health care organizations
	Link patients with resources and organizations that can address their unmet needs	
	Collaborate with social workers, resource specialists, and community health workers to identify existing resources both within and outside of healthcare institutions	Local/state-level policy, health care organizations
	Partner with community organizations that provide services to vulnerable populations	Local/state-level policy, health care organizations
	Advocate for additional funding to support patients in addressing their unmet needs	Local, state, and national policy

Immediate Symposium Perspectives

At the conclusion of HCC-CARE, 55 (83%) of participants completed an online survey to provide feedback on the symposium ([Supplemental Figure 2](#)). The vast majority of survey respondents reported somewhat or strongly agreeing that the symposium improved their understanding of barriers to diagnosis and treatment faced by patients with HCC (n=49, 89%), the goals that must be achieved to advance equity among patients at risk for or diagnosed with HCC (n=52, 95%), and the necessary actions and steps to advance equity among patients at risk for or diagnosed with HCC (n=52, 95%). Over 70% of participants committed to engaging in each of the four symposium themes (n=41, 75% for HCC screening; n=39, 71% for multi-institutional registry; n=39, 71% for linkage to support services; and n=48, 87% for community engagement and education). In free-text responses, some participants also highlighted the importance of addressing treatment-related disparities among patients with HCC and expressed interest in engaging in these efforts as well.

Conclusions and Next Steps

HCC-CARE represented the first step in creating comprehensive and collaborative solutions for achieving equitable HCC outcomes in Boston. The symposium successfully accomplished three objectives. First, HCC-CARE *established a knowledge base and raised the saliency of HCC disparities*. HCC disparities receive a fraction of the attention paid to breast or colorectal cancer disparities. By establishing a factual framework that described HCC treatment, outcomes, and drivers of disparities, we fostered a shared understanding of the impact of HCC disparities in our region among

primary care clinicians, specialists and public health officials. Second, HCC-CARE *created a multi-institutional consortium of individuals committed to addressing HCC disparities*. This consortium included clinicians across the care continuum, ancillary staff such as patient navigators who are key to addressing needs in this patient population, and representation from multiple parts of the state and local government that are essential for overcoming barriers to care at all levels of influence. Third, HCC-CARE *leveraged the wide-ranging expertise of the participants to identify key goals and strategies for achieving equity in HCC outcomes*. HCC disparities manifest well before a patient develops HCC, and multi-disciplinary and multi-institutional expertise was critical for broadening the focus beyond single-center experiences with HCC treatment.

HCC-CARE was a foundational first step, but further action is imperative. More work is needed to overcome potential barriers to implementation, including funding and resource constraints, competing public health priorities, and current lack of shared infrastructure for clinical collaboration and data sharing. As such, we have set up virtual, multi-institutional committees for each theme identified in the symposium (as well as the fifth theme around HCC treatment, which emerged post-symposium) which will further develop and enact these action plans, with the objective of further advocating for HCC as a public health priority, building shared digital infrastructure across the region, and ultimately eliminating HCC disparities by 2030. We will also maintain an organizational framework to coordinate efforts within and between theme-based action plans, apply for additional funding, and expand our consortium to include roles, institutions and perspectives that were missing from the symposium. We will bolster efforts to incorporate the voice of patients and communities hit hardest by HCC (eg, Asian, Black, homeless populations, communities of substance use), as well as the community clinicians that serve these patients. Our outreach included many stakeholders who were unable to attend the symposium or whom we missed in our symposium development; we will leverage the new relationships fostered during HCC-CARE, particularly among the community engagement and outreach committee, to incorporate these voices going forward.

While HCC-CARE was organized to address HCC disparities in the Greater Boston region, we believe that the symposium offers several lessons that are broadly applicable to other settings: 1) the strategic design of the meeting organized around an objective of identifying actionable goals; 2) the diverse stakeholders across role groups, healthcare institutions and state and local government, that ensure broad perspectives; 3) the priority goals and strategies identified by participants that are applicable in all US communities; and 4) how a symposium dedicated to action propelled collaborative efforts to address HCC disparities. We encourage HCC communities in other cities and states to build from our experience and replicate this process, developing and implementing plans to address HCC disparities tailored to their local context.

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Please see [Supplementary Materials](#) for the collaborators list.

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Disclosure

KSL has received honoraria from Wiley and has an immediate family member who is employed by and owns stock in GlaxoSmithKline. AB reports consulting with Agenus and Sirtex and conducts institutional research with Seagen, AstraZeneca, Agenus and Geistlich. CM reports funding related to hepatocellular carcinoma disparities from the American Cancer Society, Flatiron Health and AstraZeneca. The authors report no other conflicts of interest in this work.

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