

## American College of Cardiology.

## **Top 10 Takeaways:**

ACC's Advances in Hypertrophic Cardiomyopathy (HCM) Heart House Roundtable sought to identify and address opportunities and challenges in the delivery of guideline-directed care. Critical issues inhibiting care and proposed opportunities to address them include the following:

01	HCM is underrecognized with many missed opportunities, including focus primarily on obstructive disease	We should strive to increase awareness of unexplained left ventricular hypertrophy in all varieties. Understanding and expanded treatment strategies for both left ventricular outflow tract obstruction and non-obstructive HCM is recommended.
02	Completion of family genetic screening is low	Improved access to genetic counselors could address this gap. This could be mitigated through telehealth and elimination of interstate practice restrictions. Genetic counselor autonomy can contribute to access. Currently, the Access to Genetic Counselor Services Act, introduced in 2021, addresses these ideas.
03	With the release of the 2020 ACC/AHA HCM Guideline, updated patient education tools are needed to support recommendations for shared decision-making, particularly for understanding sudden cardiac death risk stratification	This is being addressed with an updated risk calculator in the ACC's Guideline App as well as the <i>Journal of the American College of Cardiology</i> Genetic Testing Interactive Tool. Importantly, patients and clinicians should be aware that lack of symptoms is not equivalent to lack of sudden cardiac death risk.
04	Implementation of novel therapies will require patient, clinician, and industry collaboration	Collaboration and communication between industry and prescribing clinicians will promote safe, effective, and appropriate medication access. Similarly, engagement across numerous medical specialties should be sought as novel classes of therapeutics enter the clinical arena. Broad partnership between payers, industry, health systems, government, and clinicians is required to meet the challenge to optimize accessibility for all patients.
05	Traditional heart failure endpoints (e.g., hospitalization, death, peak VO2, New York Heart Association [NYHA]) can be difficult to assess in this patient population	Clinical trial endpoints should address patient experience, such as symptom burden and functionalities. Therefore, design of future HCM trials should explore patient engagement and patient reported outcomes as primary measures for efficacy. This will require engagement with regulatory partners for study design and advocacy from academic collaboratives to establish evidence bases from which such approaches can be drawn.
06	Though mild-to-moderate intensity recreational exercise has proven benefit for cardiorespiratory fitness, physical function, and quality of life in HCM and even has a Class I, Level of Evidence B-NR recommendation in the latest guidelines, cardiac rehab is still not covered for this condition	There could be consideration to lobby for this. This is an area for shared interest between professional and patient organizations and is of paramount importance for near-term guideline revisions.
07	Access to specialty care is unequal, and racial differences in disease expression and adverse clinical outcomes exist among patients with HCM	There should be a concerted effort to include a diverse patient population in clinical trials, outcomes studies, and genetic testing. Mechanisms for outreach and education are required. Incentivization for broadening access might be included as a metric in program evaluations.
08	Women are underrepresented at HCM centers and are more likely to die from advanced heart failure related to HCM than men	There is the need to further science, refine diagnostic strategies, and consider sex as a key variable in outcome studies. Improving access and outreach for specialized HCM care for women and reassessing diagnostic thresholds should also be emphasized.
09	There is a need to increase the number of advanced professionals in HCM specialty centers and increase diversity in regard to sex, gender, race, ethnicity, and role in the care team	Dedicated subspecialty training for cardiomyopathy broadly, and HCM specifically is needed. Mentoring opportunities for minorities and women should be encouraged. This might be accomplished with collaboration between the ACC and organizations such as the Association of Black Cardiologists.
10	Professional pride, compensation, and referral outside of one's health system are disincentives for referral to HCM specialty centers	These could be overcome by educating general cardiologists on the value specialty care centers provide by improving outcomes.