Cardiovascular Disease Working Group
HCM Initiative
2026 MEETING SUMMARY

The Alliance for Patient Access hosted its annual meeting for the Hypertrophic Cardiomyopathy Initiative of its Cardiovascular Disease Working Group on July 31-August 1 in Washington, DC. Clinicians convened to discuss barriers impacting patients with hypertrophic cardiomyopathy, or HCM, and opportunities to improve access to appropriate care.

UTILIZATION MANAGEMENT

Prior Authorization and Reauthorization

Prior authorization remains one of the most significant access barriers clinicians encounter when treating patients with HCM. Meeting participants described the time required to complete paperwork, appeal denials and communicate with insurers, often without reimbursement for that work. Clinicians reported handling the copious amounts of unpaid administrative work that goes into appeals each week — a burden that is often shared with their staff. These requirements can also affect patients who need ongoing treatment.

Reauthorization requires clinicians to repeatedly demonstrate that a treatment is medically necessary, even when a patient is already benefiting from it. Delays can interrupt care and add to the administrative burden of managing a chronic condition.

Step Therapy

Step therapy can require patients to try insurer-preferred treatments before gaining access to the therapy selected by their clinician. In some cases, patients may be required to try an off-label treatment before receiving an FDA-approved medication. The discussion emphasized the importance of preserving clinicians' ability to select treatments based on an individual patient's needs rather than a predetermined sequence established by an insurer.

Non-medical Switching

Clinicians also discussed non-medical switching, which occurs when a patient's treatment is changed for reasons unrelated to their health or their clinician's recommendation.

For patients who are stable on treatment, a switch can disrupt continuity of care and require additional appointments, monitoring or administrative work. One clinician highlighted the financial implications of switching, noting that the costs associated with changing treatment extend beyond the price of the medication itself. Participants emphasized that treatment decisions should remain between patients and their clinicians, particularly when a therapy is working as intended.

AWARENESS OF HCM

Despite progress in recent years, patient and clinician awareness of HCM remains a challenge. Patients may have few distinguishable symptoms or symptoms that resemble other conditions, contributing to missed or delayed diagnoses. Patients may also be unaware of a genetic predisposition to HCM. Participants emphasized the need for continued education among both patients and clinicians. One clinician said education for patients and community cardiologists should remain a priority. Increasing awareness is particularly important as HCM treatment evolves to include new diagnostic tools and treatment options.

ACCESS TO SPECIALISTS AND TELEHEALTH

Where a patient resides can play a significant role in whether they can access proper HCM care. Participants described "access deserts," where specialized HCM care is concentrated in certain regions while other areas have few options. Centers of Excellence have helped connect patients with multidisciplinary teams that may include HCM specialists, genetic counselors and imaging experts. But these centers are not available in every state, leaving geographic gaps in access. The shortage is particularly pronounced for children. One clinician noted that pediatric HCM specialists are extremely rare and expressed a desire to expand both the specialty and access to care for pediatric patients.

Telehealth can help bridge some of the geographic gaps that make accessing HCM specialists difficult. Participants expressed support for maintaining telehealth access but also raised concerns about reimbursement and coverage. One clinician highlighted the need for greater use of telehealth, including supporting patients' mental health needs.

RISK EVALUATION AND MITIGATION STRATEGIES

Risk Evaluation and Mitigation Strategies, or REMS, are FDA-required safety programs for certain medications. While clinicians recognized the role of REMS in promoting safe treatment, participants discussed how program requirements can also complicate access. Enrollment requirements, monitoring, costs and administrative responsibilities can create challenges, including patient adherence. One clinician emphasized that the health care system should make it easier for patients to remain compliant with treatment requirements rather than simply adding additional requirements. Recent changes to the REMS requirements have reduced some monitoring requirements. Participants acknowledged the potential for these changes to ease the burden on patients and practices while maintaining appropriate safety monitoring.

NEXT STEPS

Meeting participants identified opportunities to continue advocating for policies that improve access to HCM care, emphasizing the value of clinician advocacy. Personal experiences from clinical practice can help policymakers understand how insurance restrictions and other barriers affect patients. Federal bills such as the Pharmacists Fight Back Act, Improving Seniors' Timely Access to Care Act, HELP Copays, Safe Step Act and state utilization management bills represent actionable opportunities for clinicians to impact health policy on behalf of their patients.

GET INVOLVED

To learn more about AfPA's Hypertrophic Cardiomyopathy Initiative, contact Payton Marvin at **pmarvin@allianceforpatientaccess.org** and visit our website at **AllianceForPatientAccess.Org**