



Cardiovascular Disease Working Group

2024 Meeting Summary

The Alliance for Patient Access convened the inaugural meeting of its Hypertrophic Cardiomyopathy Initiative of the Cardiovascular Disease Working Group on March 1-2, 2024 in Washington, DC. Comprised of a diverse array of clinician stakeholders, the group explored HCM care, identifying current and future access challenges and potential solutions.

HCM is a heart condition marked by thickened cardiac muscle that can impede the heart's ability to pump blood. HCM is the most common inherited cardiovascular disorder, impacting one in every 250 people. Symptoms include chest pain, shortness of breath, palpitations and fainting. While historical treatment options have mostly been surgical or symptom management, new options could drastically change the way HCM is treated.

Current State of HCM Care

Experts at the meeting shared that HCM has become increasingly treatable, thanks to significant strides in research that have yielded new therapies. Despite these advances, group members emphasized that challenges remain in ensuring patients receive the care they need.

Insurers' reluctance to provide adequate coverage for essential components of HCM management poses a significant challenge. Genetic testing, participants said, can be a powerful tool to identify hereditary factors that cause HCM. But too often patients cannot access testing. Echocardiograms are another sticking point. Frequent echocardiograms are required by the FDA as a part of the REMS process for newer HCM treatments. Coverage for these tests, which help clinicians monitor disease progression and treatment efficacy,

meets resistance from insurers, however. Participants emphasized the importance of improving REMS education among payers to ensure that patients can receive the appropriate tests in a timely manner.

Beyond thorough monitoring, HCM management also necessitates extensive patient counseling. Clinicians mentioned that while HCM Centers of Excellence may have the infrastructure and capabilities to provide holistic HCM care, they may not be accessible to all patients. Proper coordination with community cardiologists for ongoing disease management remains difficult yet critically important.



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Barriers to Optimal Care

Insurance barriers impede optimal HCM care, group members agreed.

- **Prior authorization** emerged as a significant hurdle, with insurers often failing to grasp the necessity of stress echocardiograms in disease management. Increasing awareness among payers to recognize the unique requirements for many HCM patients to receive regular echocardiographs is paramount to patients receiving appropriate care.
- **Copay diversion programs**, participants said, can worsen patients' financial burdens. Programs like copay accumulators or copay maximizers often catch patients off guard and may negatively impact their ability to access their medications. Alternative funding programs create another barrier in which patients may need to seek external options to cover their treatments.
- **Formulary exclusions and non-medical switching** were also identified as barriers that disproportionately affect vulnerable populations. As more treatments become available, patients and providers need access to the treatment that they deem is the most appropriate for each individual.

Opportunities for Reform

Group members discussed potential reforms to address these challenges. Clinician advocacy will be critical to ensuring HCM patients can access the care they need.

- **Utilization Management Reform.** For issues like prior authorization, step therapy, non-medical switching and cost sharing, legislative efforts at the state and federal level aim to place guardrails around these practices.
- **Enhanced Patient Education.** Participants noted that fostering awareness and understanding of HCM could empower more informed decision-making and advocacy.
- **Telehealth Expansion.** Participants emphasized the support that could result

from expanded coverage and reimbursement policies for telehealth services. As many patients require care from specialists, the ability to access an HCM Center of Excellence is critical. Virtual visits, when appropriate, could allow more patients to receive regular care from a HCM specialist.

- **Mental Health Considerations.** When patients are diagnosed with HCM, their lives change. Ensuring that a proper care team is in place to address any potential impact to a patient's mental health is crucial to patient-centered care.
- **Specialty Pharmacies.** For patients taking newer therapies, specialty pharmacies are a critical stakeholder. Increasing education and awareness of the role that specialty pharmacies play in proper care coordination can help to ensure appropriate access.

Next Steps

The launch of the HCM initiative is just the start. The working group and its members are ready to engage with policymakers, develop ways to improve access to care and support access for the HCM patient community. Additional materials will be developed to encourage education and awareness, advance access to care and spotlight policies that further patient access. To learn more about AfPA's HCM Initiative, contact Margaret Uhler at muhler@allianceforpatientaccess.org.



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