Managed care approaches to address unmet patient needs in idiopathic hypersomnia (IH)

AMCP | MARKET INSIGHTS

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BACKGROUND

Idiopathic hypersomnia (IH) is a sleep disorder that causes excessive daytime sleepiness, sleep inertia, and substantially decreased quality of life, and which affects nearly 100,000 Americans by some estimates. Comorbidities are frequent, and delays in diagnosis complicate treatment. IH is primarily managed with off-label stimulants and wakefulness-promoting agents; currently, lower sodium oxybate is the only Food and Drug Administration (FDA)-approved treatment option.

OBJECTIVE

To gain insights into health plan best practices for IH diagnosis and management.

METHODS

A multidisciplinary virtual panel was convened by AMCP in November 2024, bringing together 9 participants, including representatives from health plans, a patient advocacy group, and a sleep medicine specialist, among others. The program included live polling to capture quantitative feedback and facilitated discussions to gather qualitative insights.

RESULTS

Panelists acknowledged that disease burden and delays in diagnosis significantly impact the quality of life of patients with IH and identified improving timely, accurate diagnoses as a key issue in IH. Regarding drug management interventions, diagnosis by a sleep medicine specialist is required as part of the coverage criteria according to most panelists, as is an adequate trial of lower-cost generic options prior to coverage of branded agents. Panelists appreciated the utility of FDA approval; however, in a condition like IH, where most recommended medications are off-label but have a supporting body of evidence for their use, consensus guidelines are often the primary driver of coverage decisions rather than solely FDA approval. Panelists suggested the following health plan best practices as part of an overall management strategy for IH: provider education, facilitating referrals to sleep medicine specialists and laboratories, reviewing coverage policies according to the FDA label and available consensus guidelines, and evaluating the safety of individual medications and the presence of comorbidities.

Key Insights

Diagnostic challenges

- Panelists acknowledged that disease burden and delays in diagnosis significantly impact the QoL of patients with IH.
- Improving timely, accurate diagnoses is a key issue in IH.

Coverage decisions

- Panelists emphasized that payers must prioritize elements that can be objectively measured for making coverage decisions.
- Panelists appreciated the utility of FDA approval; however, in a condition like IH, where most of the recommended medications are off-label but have a supporting body of evidence for their use, consensus guidelines are often the primary driver of coverage decisions rather than solely FDA approval.

Coverage criteria

- The current expectation of the marketplace is for coverage criteria to apply to all high-cost medications; although payers recognized the need to balance this with efforts to mitigate unnecessary barriers to care.
- Most panelists indicated that diagnosis of IH by a specialist is part of their coverage criteria, whereas incorporating the safety of individual medications for IH and the existence of comorbidities into a management strategy is more nuanced.

Payer Best Practices in IH Suggested by the AMCP Market Insights Panel

Action	Description
Facilitate timely, accurate diagnosis of IH	This may include network PCP education, referral to care management, and consideration of new diagnostic technologies, as examples
Consider the use of real-world evidence with validated patient-reported outcomes to better incorporate patient QoL into coverage decisions	The QoL burden is significant in IH. Although it can be difficult to quantify for use in coverage decisions, real-world evidence using validated patient-reported outcomes can help mitigate this difficulty
Advocate for up-to-date guidelines and treatment protocols to drive more precise coverage decisions	Consensus guidelines are often the primary driver of coverage decisions in a condition like IH, in which most of the recommended medications are off-label but have a supporting body of evidence for their use. Also, treatment protocols providing an order in which medications should be used would allow more precise coverage decisions
Evaluate the safety of individual medications and the presence of comorbidities as part of an overall management strategy for IH	Addressing these may not require specific criteria in coverage policies but may include other interventions, such as stimulant stewardship programs or a holistic care management approach to sleep issues for all chronic conditions
Assess prior authorization processes and coverage criteria for opportunities to streamline	Although the current expectation of the marketplace is for coverage criteria to apply to all high-cost medications, there is a need to balance this with efforts to mitigate unnecessary barriers to care

IH=idiopathic hypersomnia; PCP=primary care physician; QoL=quality of life.

CONCLUSIONS

These AMCP Market Insights program findings underscore the need for earlier IH diagnoses, which can be achieved through primary care education and streamlined referrals to sleep specialists. Sleep specialists can facilitate optimal treatment by assessing individual patient characteristics against available off-label and FDA-approved agents.

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Reference: Flavin B, Wolff D, Contreras Z, Haumschild R, Kimmel D, Kobernick M, Rahman F. AMCP Market Insights: Payer best practices for timely diagnosis and optimal management of idiopathic hypersomnia. *J Manag Care Spec Pharm*. 2025;31(9):1-9.