

Title: Diagnosed Prevalence of Idiopathic Hypersomnia Among Adults in the United States

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ABSTRACT

Introduction: Idiopathic hypersomnia (IH) is a rare neurologic disorder that can cause debilitating symptoms, including excessive daytime sleepiness, severe sleep inertia, prolonged nighttime sleep, long and unrefreshing naps, and cognitive dysfunction. Research reporting the burden of IH is scant. The objective of this study was to estimate the diagnosed prevalence of IH among US adults between 2019 and 2021.

Methods: Symphony Integrated Dataverse[®] administrative claims between November 2015 and December 2021 were analyzed. Eligible patients were aged ≥ 18 years and had 1 medical or prescription claim in the calendar year of interest (2019, 2020, or 2021) and in the year prior. Diagnosed prevalence included all IH cases observed in eligible patients through the last day of the year of interest. IH cases were defined as eligible patients with ≥ 1 medical claim containing an IH diagnosis code in any position before or during the calendar year of interest, and no history of cataplexy. Unweighted prevalence estimates were reported per 100,000 persons with 95% confidence intervals (CIs). Age- and sex-adjusted prevalence estimates were calculated using 2019 US Census Bureau data.

Results: Over 158, 168, and 187 million adults were eligible for assessment of diagnosed prevalence of IH in 2019, 2020, and 2021, respectively. The unweighted diagnosed prevalence of IH was 32.12 per 100,000 persons (CI: 31.84, 32.40), 35.71 per 100,000 persons (CI: 35.43, 36.00), and 37.03 per 100,000 persons (CI: 36.75, 37.30) in 2019, 2020, and 2021, respectively. The estimated standardized numbers of US adults diagnosed with IH were 80,603 (CI: 80,048, 81,161), 89,539 (CI: 88,954, 90,127), and 92,139 (CI: 91,545, 92,736) in 2019, 2020, and 2021, respectively.

Conclusion: To our knowledge, this is the most recent study to estimate diagnosed prevalence of IH in US adults. It is uncertain what proportion of IH cases remain undiagnosed considering the under-recognition of this condition, low utilization of sleep testing, and concerns over the reliability of multiple sleep latency testing. Furthermore, recent studies suggest only a subset of patients with IH actively seek medical care for their condition. Given its impact on patients' lives, further research to improve surveillance of IH symptoms is needed.

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Disclosures

R Saad is a full-time employee of Jazz Pharmaceuticals who, in the course of this employment, has received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc.

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RK Bogan is a shareholder of Watermark Medical and Healthy Humming, LLC; serves on the board of directors for Watermark; is a medical consultant to Jazz Pharmaceuticals, Harmony Biosciences, Avadel Pharmaceuticals, Takeda, and Oventus; has conducted industry-funded research for Avadel, Axsome, Bresotec, Bayer, Idorsia, Suven, Jazz, Balance, NLS, Vanda, Merck, Eisai, Philips, Fresca, Takeda, LivaNova, Roche, Sanofi, Sommetrics, and Noctrix; and is on speakers bureaus for Jazz, Eisai, and Harmony.

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P Lillaney is a former full-time employee of Jazz Pharmaceuticals who, in the course of this employment, has received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc.

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