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Diagnosed Prevalence of Idiopathic Hypersomnia Among Adults in the United States

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Introduction

- Idiopathic hypersomnia 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[1]
- National estimates of the prevalence of idiopathic hypersomnia are difficult to obtain because of the absence of a validated biomarker and differing diagnostic criteria—namely, differences in the need for diagnostic sleep testing[1-4]
- Despite this difficulty, the literature estimates the prevalence of idiopathic hypersomnia in the US adult population to be 0.002% to 0.010%[2]
- A previous investigation showed a 32% increase in the 2-year limited-duration prevalence of idiopathic hypersomnia, from 7.8 per 100,000 persons in 2013 to 10.3 per 100,000 persons in 2016[5]
- Use of large healthcare databases allows for high statistical precision, based on demographic factors, in estimating the national prevalence of idiopathic hypersomnia[5]

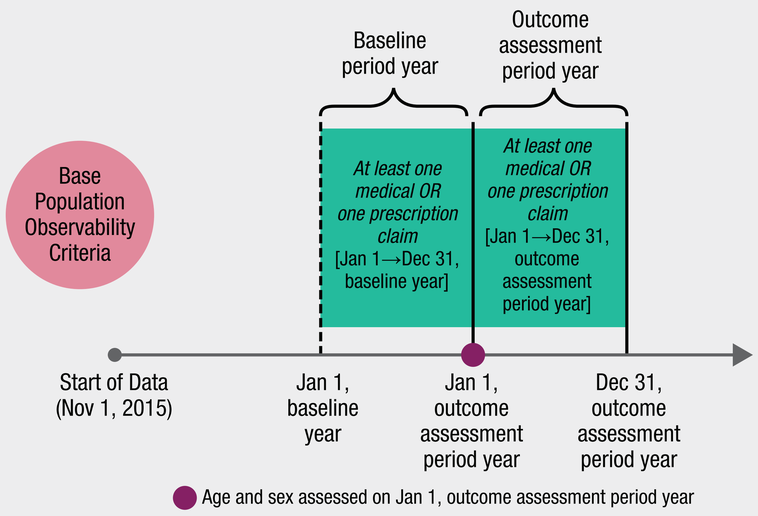
Objective

- The objective for this study was to provide the most recent estimate of the diagnosed prevalence of idiopathic hypersomnia among US adults between 2019 and 2021

Methods

- Symphony Integrated Dataverse® (IDV) administrative claims between November 2015 and December 2021 were analyzed
- Eligible patients were ≥18 years of age and had ≥1 medical or prescription claim in the calendar year of interest (2019, 2020, or 2021) and in the year prior (**Figure 1**)
- Diagnosed prevalence included all cases of idiopathic hypersomnia occurring through the last day of the year of interest among all eligible patients
- Cases of idiopathic hypersomnia were defined as eligible patients with ≥1 medical claim containing a diagnosis code for idiopathic hypersomnia (ICD-9-CM, 327.11, 327.12; ICD-10-CM, G47.11, G47.12), and no history of cataplexy[6,7]
- 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 to estimate standardized numbers of US adults diagnosed with idiopathic hypersomnia

Figure 1. Criteria for Prevalence Base Population



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Results

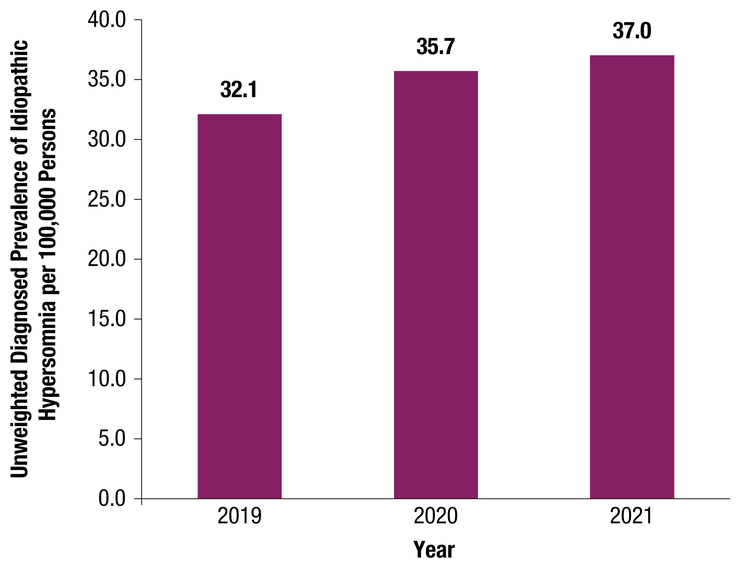
Table 1. Baseline Demographic Characteristics of At-Risk Observable Population in Symphony IDV® in 2019, 2020, and 2021

	2019	2020	2021
Population at-risk[a], N	158,619,469	168,154,753	187,774,494
Age[b], years			
Mean (SD)	50.7 (17.4)	51.0 (17.7)	50.6 (18.0)
Median (IQR)	52.0 (36.0, 65.0)	53.0 (36.0, 66.0)	52.0 (35.0, 65.0)
Sex[b], n (%)			
Female	93,176,758 (58.7)	98,311,972 (58.5)	107,935,421 (57.5)
Male	65,442,711 (41.3)	69,842,781 (41.5)	79,839,073 (42.5)
Region[b] (US), n (%)			
Northeast	29,602,352 (18.7)	31,236,264 (18.6)	34,622,178 (18.4)
Midwest	34,855,559 (22.0)	36,759,288 (21.9)	40,185,581 (21.4)
South	63,006,078 (39.7)	66,420,472 (39.5)	73,551,612 (39.2)
West	28,579,254 (18.0)	30,697,273 (18.3)	35,487,049 (18.9)
Other	1,422,414 (0.9)	1,527,047 (0.9)	1,771,053 (0.9)
Missing	1,153,812 (0.7)	1,514,409 (0.9)	2,157,021 (1.1)

IDV, Integrated Dataverse; IQR, interquartile range; SD, standard deviation.
[a]Patients were considered at-risk if they had at least 1 medical or prescription claim in the baseline period year and at least 1 medical or prescription claim in the outcome assessment period year.
[b]Age, sex, and region assessed on January 1 of the respective years.

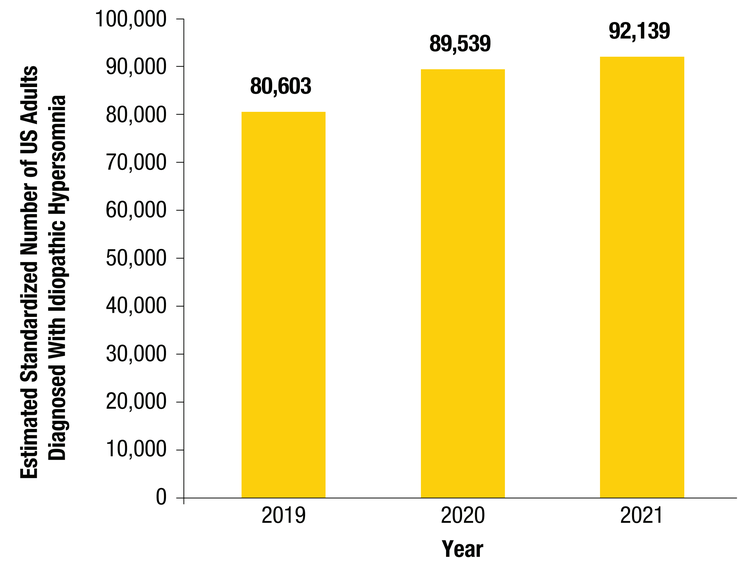
- Over 158 million adults in 2019, 168 million adults in 2020, and 187 million adults in 2021 were eligible for assessment of diagnosed prevalence of idiopathic hypersomnia
- The mean age (standard deviation) of eligible adults was 50.7 (17.4) years in 2019, 51.0 (17.7) years in 2020, and 50.6 (18.0) years in 2021, and most were female (58.7% in 2019, 58.5% in 2020, 57.5% in 2021)

Figure 2. Unweighted Diagnosed Prevalence of Idiopathic Hypersomnia



- The unweighted diagnosed prevalence of idiopathic hypersomnia was 32.1 per 100,000 persons (95% CI: 31.8, 32.4) in 2019, 35.7 per 100,000 persons (95% CI: 35.4, 36.0) in 2020, and 37.0 per 100,000 persons (95% CI: 36.8, 37.3) in 2021

Figure 3. Estimated Standardized Numbers of US Adults Diagnosed With Idiopathic Hypersomnia



- The estimated standardized numbers of US adults diagnosed with idiopathic hypersomnia were 80,603 (95% CI: 80,048, 81,161) in 2019, 89,539 (95% CI: 88,954, 90,127) in 2020, and 92,139 (95% CI: 91,545, 92,736) in 2021

Conclusions

- The findings of this study are consistent with previously reported increases in the prevalence of idiopathic hypersomnia in the US adult population[5]
- As recent studies suggest that only a subset of patients with idiopathic hypersomnia actively seek medical care for their condition, prevalence estimates in this investigation may underestimate the true prevalence of idiopathic hypersomnia in the population[8]
- Future research is needed to evaluate potential heterogeneity in trends across time, to inform surveillance efforts and understanding of potential causes for the prevalence increase observed, and to clarify the burden of disease of idiopathic hypersomnia in the general population

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