

Physician Perspective on Idiopathic Hypersomnia: Awareness, Diagnosis, and Impact on Patients

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Introduction

- Idiopathic hypersomnia is a debilitating central disorder of hypersomnolence characterized by excessive daytime sleepiness (EDS), severe sleep inertia, and prolonged nighttime sleep¹
- Diagnostic criteria for idiopathic hypersomnia require the presence of EDS for at least 3 months and objective confirmation of increased sleep propensity¹
 - Specifically, patients must demonstrate a mean sleep latency of ≤ 8 minutes on the multiple sleep latency test, or a 24-hour total sleep time of ≥ 660 minutes confirmed with polysomnography or wrist actigraphy
 - In order to diagnose idiopathic hypersomnia, other causes of sleepiness must first be ruled out

Objectives

- The primary objectives of this study were to understand awareness of idiopathic hypersomnia, burden of disease, and barriers to diagnosis in physicians treating patients with idiopathic hypersomnia, as well as to understand communication between these physicians and their patients

Methods

- United States-based physicians completed an online survey (Toluna Inc., Norwalk, CT) between February 5 and 12, 2021 assessing familiarity with idiopathic hypersomnia (and other sleep disorders) and understanding of the diagnostic process and impact on patients' lives
 - Participating physicians were verified against the American Medical Association database and other sources based on unique identifiers (eg, Medical Education Number or National Provider Identifier)
- Eligible physicians lived in the United States; worked in general practice, neurology, psychiatry, or pulmonology, or were sleep specialists; were board certified; had been in practice for ≥ 2 years; and had treated ≥ 2 patients for idiopathic hypersomnia and ≥ 2 patients for narcolepsy
- Descriptive statistics were used to summarize all data

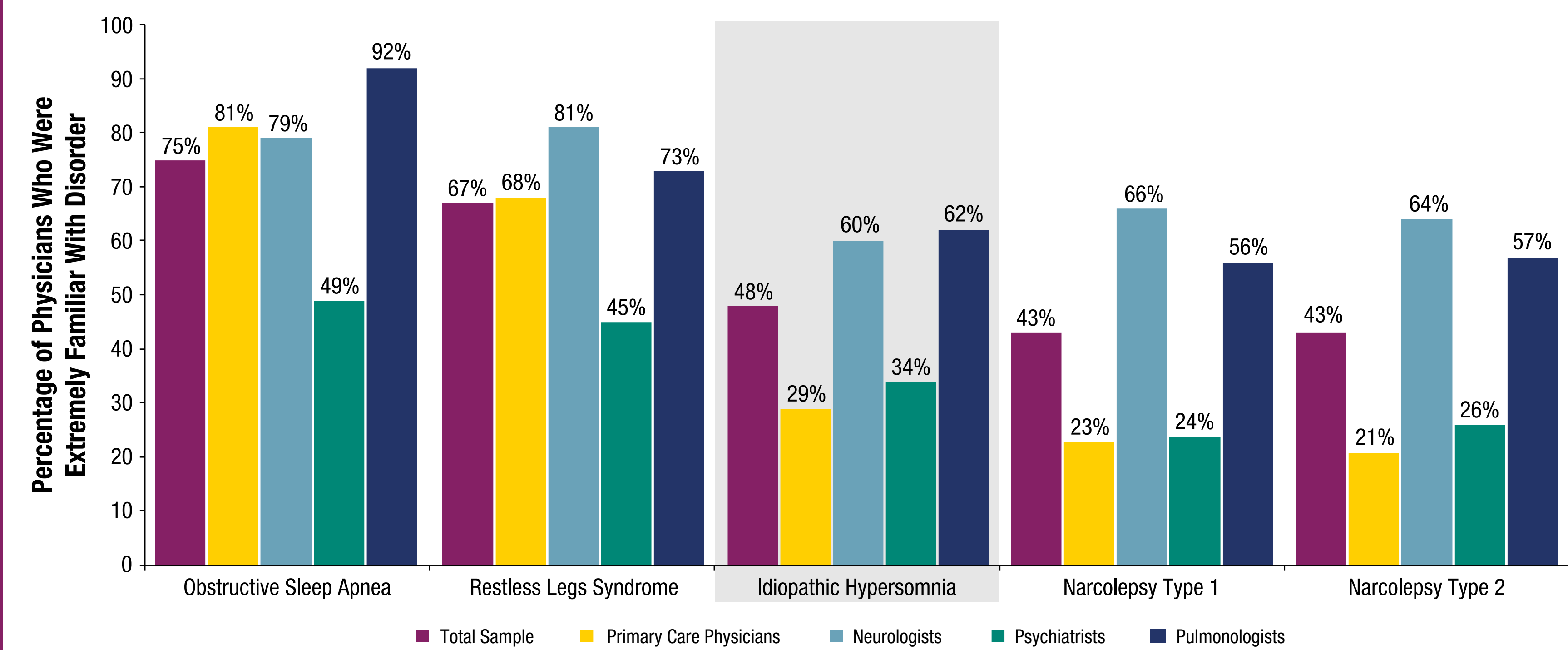
Results

Table 1. Participant Demographics

	PCPs (n=62)	Neurologists (n=67)	Psychiatrists (n=82)	Pulmonologists (n=90)	Total* (N=305)
Gender, n (%)					
Male	47 (76)	50 (75)	52 (63)	72 (80)	223 (73)
Female	15 (24)	16 (24)	28 (34)	15 (17)	76 (25)
Nonbinary	0	0	0	1 (1)	1 (<0.5)
Prefer not to answer	0	1 (1)	2 (2)	2 (2)	5 (2)
Age (years), n (%)					
25-34	4 (6)	5 (7)	6 (7)	2 (2)	17 (6)
35-44	18 (29)	24 (36)	30 (37)	24 (27)	98 (32)
45-54	21 (34)	18 (27)	17 (21)	34 (38)	91 (30)
55-64	16 (26)	11 (16)	23 (28)	20 (22)	70 (23)
≥ 65	3 (5)	9 (13)	6 (7)	10 (11)	29 (10)
White/Caucasian, n (%)	44 (71)	34 (51)	43 (52)	54 (60)	178 (58)
Board certified in sleep medicine, n (%)	9 (15)	47 (70)	25 (30)	63 (70)	148 (49)
Mean years in practice	18.5	16.2	14.7	17.4	16.6
Median number of current patients with idiopathic hypersomnia [‡]	27.5	30.0	25.0	30.5	30.0

PCPs, primary care physicians.
*Sleep specialists (n=4) were reported in the total, but not individually due to low enrollment.
[‡]Question: Approximately how many unique patients with idiopathic hypersomnia do you currently manage? Please count unique patients, not visits.

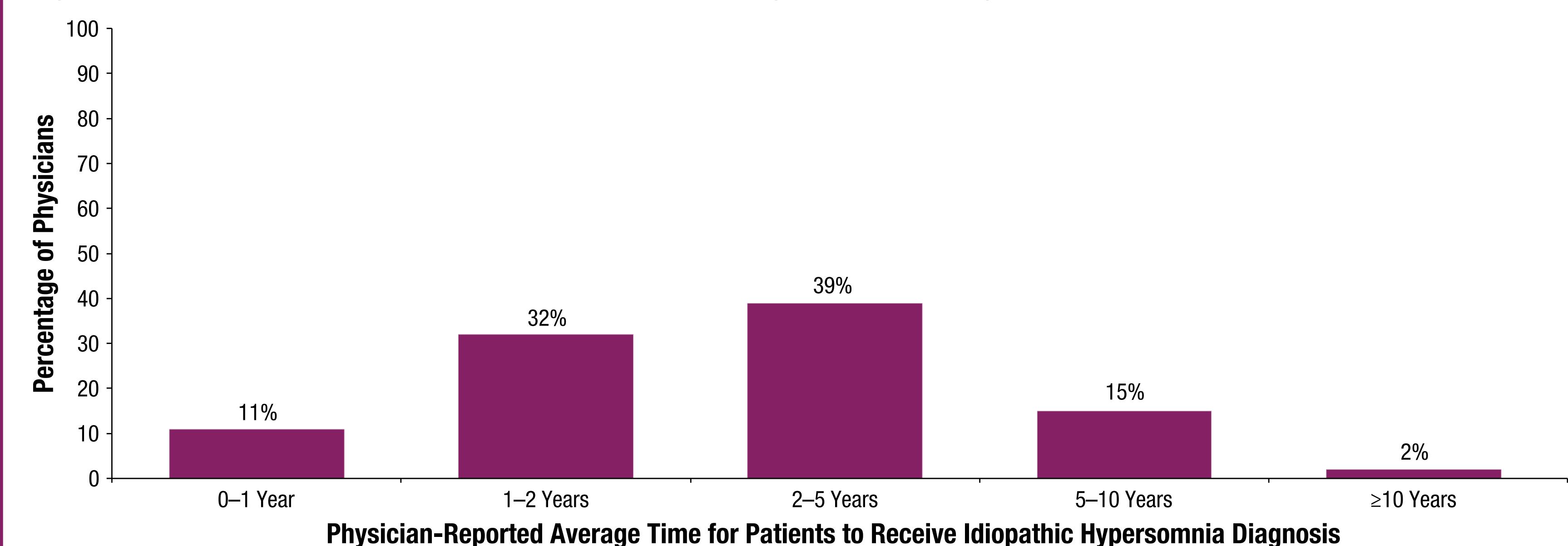
Figure 1. Physician Familiarity With Idiopathic Hypersomnia Varied by Specialty



Question: How familiar are you with each of the following?

- Physicians were not as familiar with idiopathic hypersomnia as they were with obstructive sleep apnea or restless legs syndrome
- Most healthcare providers (64%) agreed that there is an insufficient understanding of idiopathic hypersomnia among physicians

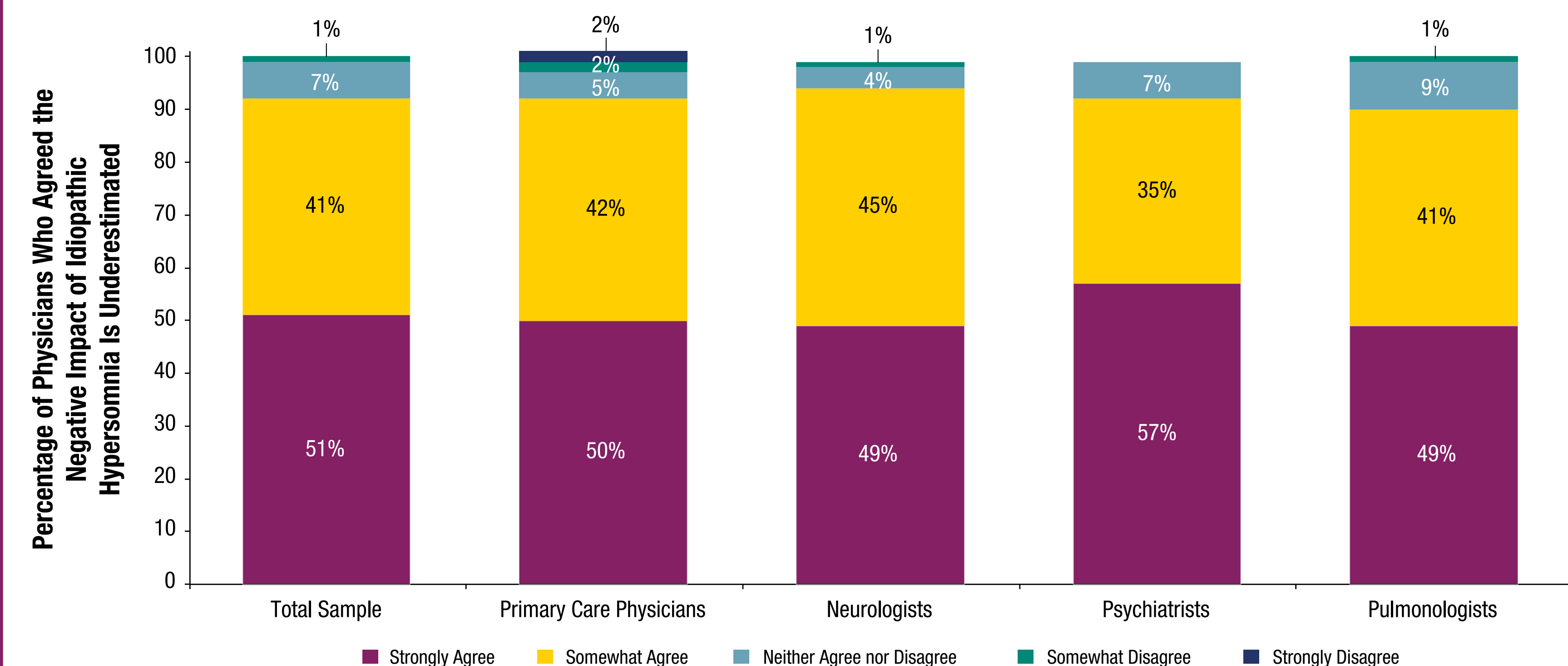
Figure 3. Most Physicians Reported That the Average Time to Diagnosis Exceeded 2 Years



Question: How long do you believe is the average time it takes patients to receive an accurate diagnosis of each disorder? (Data on idiopathic hypersomnia shown.)

- Physicians typically reported a shorter average time to diagnosis than was reported by many participants in a companion survey of patients with idiopathic hypersomnia (see poster number 157)
- Over 90% of physicians believed that idiopathic hypersomnia deserves greater recognition (somewhat agree or strongly agree)

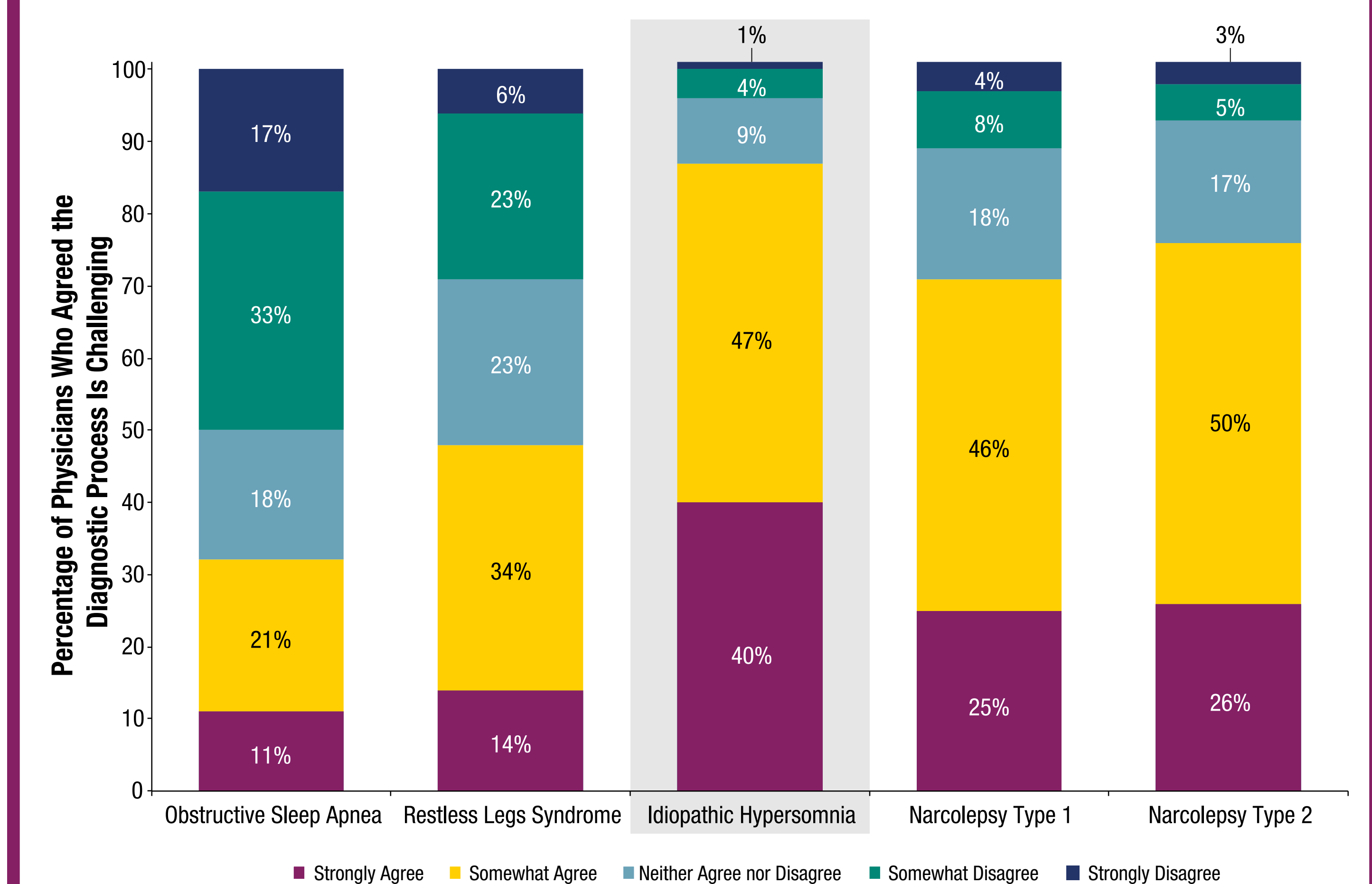
Figure 5. Most Physicians Agreed That the Negative Impact of Idiopathic Hypersomnia Is Underestimated



Question: What is your level of agreement with the following statements as they apply to each of the diseases? The negative impact that this disease has is significantly underestimated. (Data on idiopathic hypersomnia shown.)

- Most physicians (92%) reported that the negative impact of idiopathic hypersomnia is underestimated (somewhat agree or strongly agree)

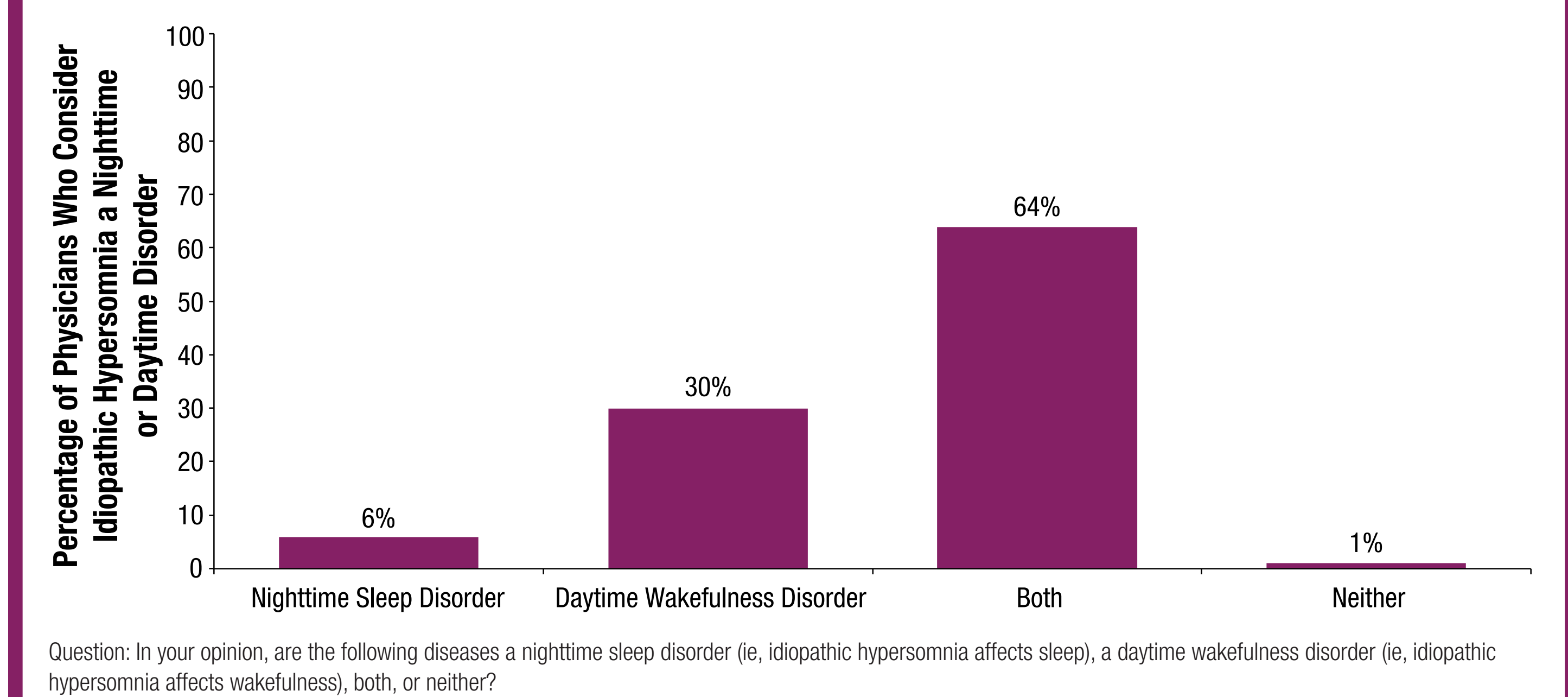
Figure 2. Most Physicians Agreed That the Diagnostic Process for Idiopathic Hypersomnia Is Challenging



Question: What is your level of agreement with the following statements as they apply to each of the diseases? The diagnosis process for this disease is challenging.

- In response to another question, almost all (91%) of the total physician sample responded that patients with idiopathic hypersomnia are often misdiagnosed (somewhat agree or strongly agree)

Figure 4. Most Physicians Considered Idiopathic Hypersomnia to Be Both a Nighttime Sleep Disorder and a Daytime Wakefulness Disorder



Question: In your opinion, are the following diseases a nighttime sleep disorder (ie, idiopathic hypersomnia affects sleep), a daytime wakefulness disorder (ie, idiopathic hypersomnia affects wakefulness), both, or neither?

Conclusions

- Among participating physicians, familiarity with idiopathic hypersomnia was lower than with obstructive sleep apnea or restless legs syndrome and similar to that with narcolepsy
- Physicians reported the diagnostic process is more challenging for idiopathic hypersomnia than for other sleep disorders; physicians agreed that many patients with idiopathic hypersomnia are misdiagnosed
- The average time to diagnosis often exceeded 2 years
- The negative impact of idiopathic hypersomnia is underestimated by healthcare providers, highlighting the need for more healthcare provider education and increased understanding of idiopathic hypersomnia, its diagnosis, and its impact on patients' lives

Reference: 1. American Academy of Sleep Medicine. *International Classification of Sleep Disorders*. 3rd ed. Darien, IL: American Academy of Sleep Medicine; 2014.

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Disclosures: M Whalen, T Steininger, and N Dronamraju are full-time employees of Jazz Pharmaceuticals who, in the course of this employment, have received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc. B Roy and D Enson have no financial conflicts of interest to disclose.



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