

Presentation to Wake Up Narcolepsy

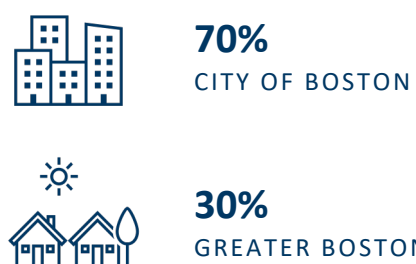
## Narcolepsy Awareness Survey

Insights from 100 physicians treating narcolepsy in children and adolescents in the Greater Boston Area

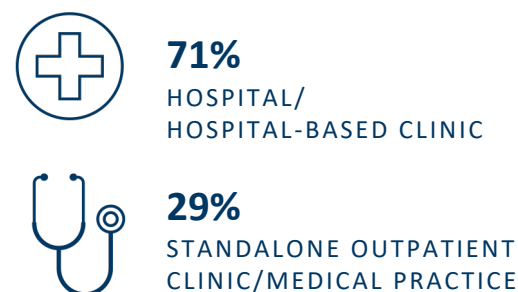
# Methodology/Sample Details

FTI surveyed 100 practicing physicians in the greater Boston area who diagnose or treat narcolepsy in children and adolescents. The 12-minute survey was administered online and fielded September 1<sup>st</sup>-14<sup>th</sup>, 2022.

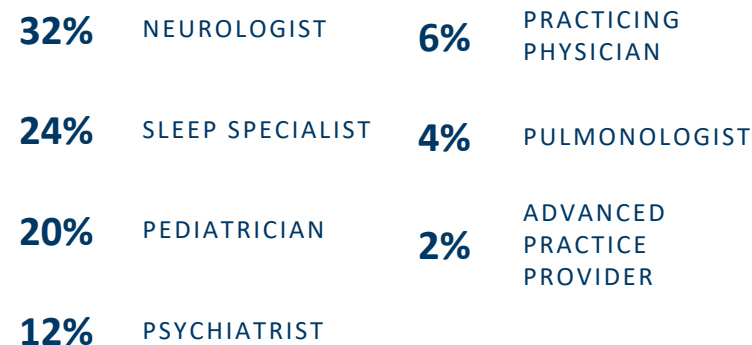
## Practice Location



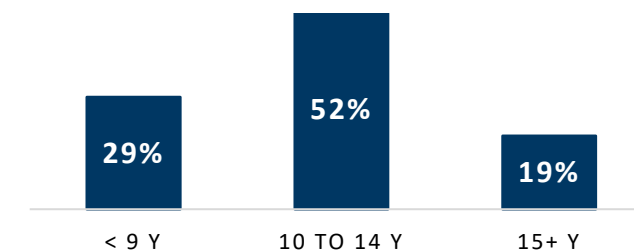
## Practice Type



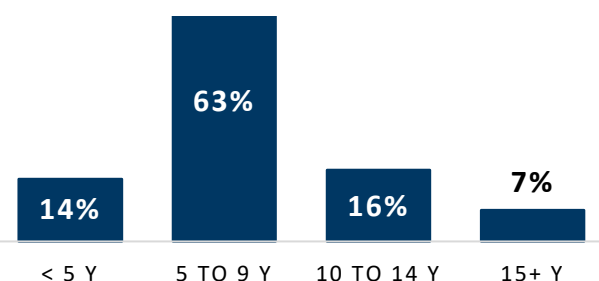
## Specialty



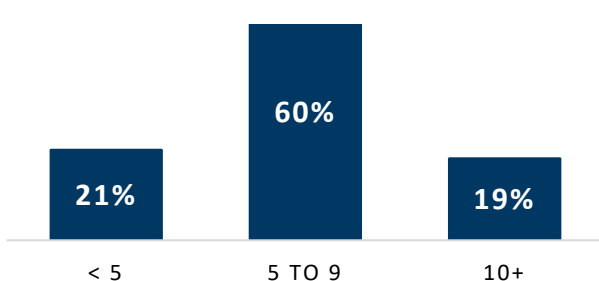
## Experience in Medical Field



## Experience Treating Narcolepsy



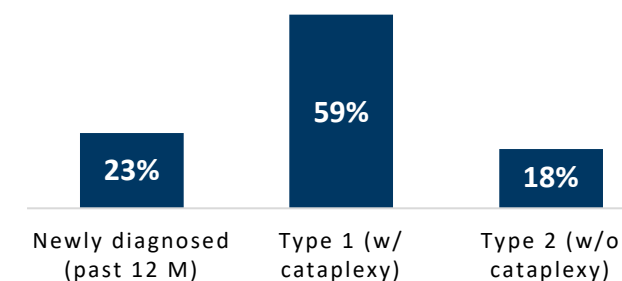
## Narcolepsy Patients Managed



## Patient Base



## Narcolepsy Type Treated



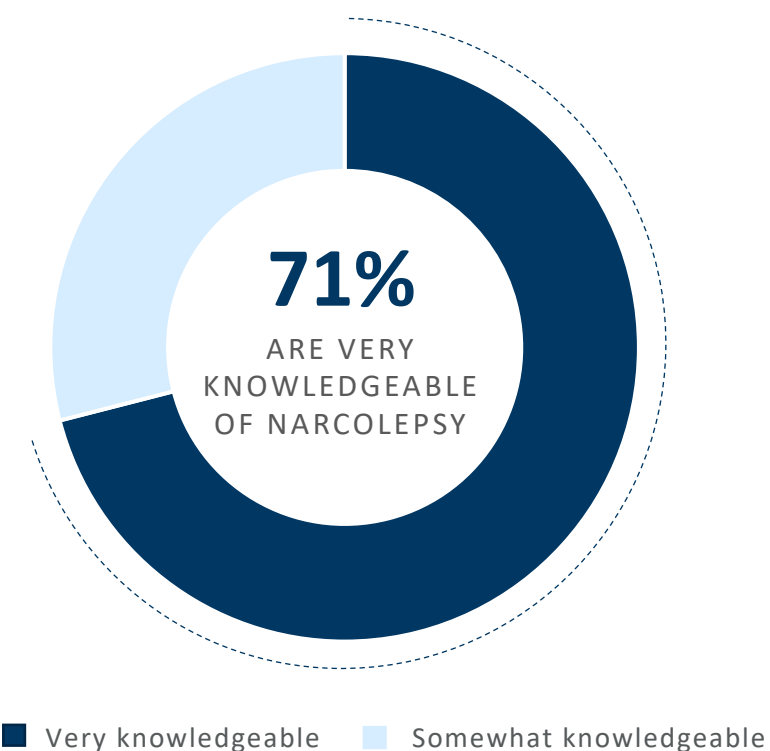


# FTI Survey Findings

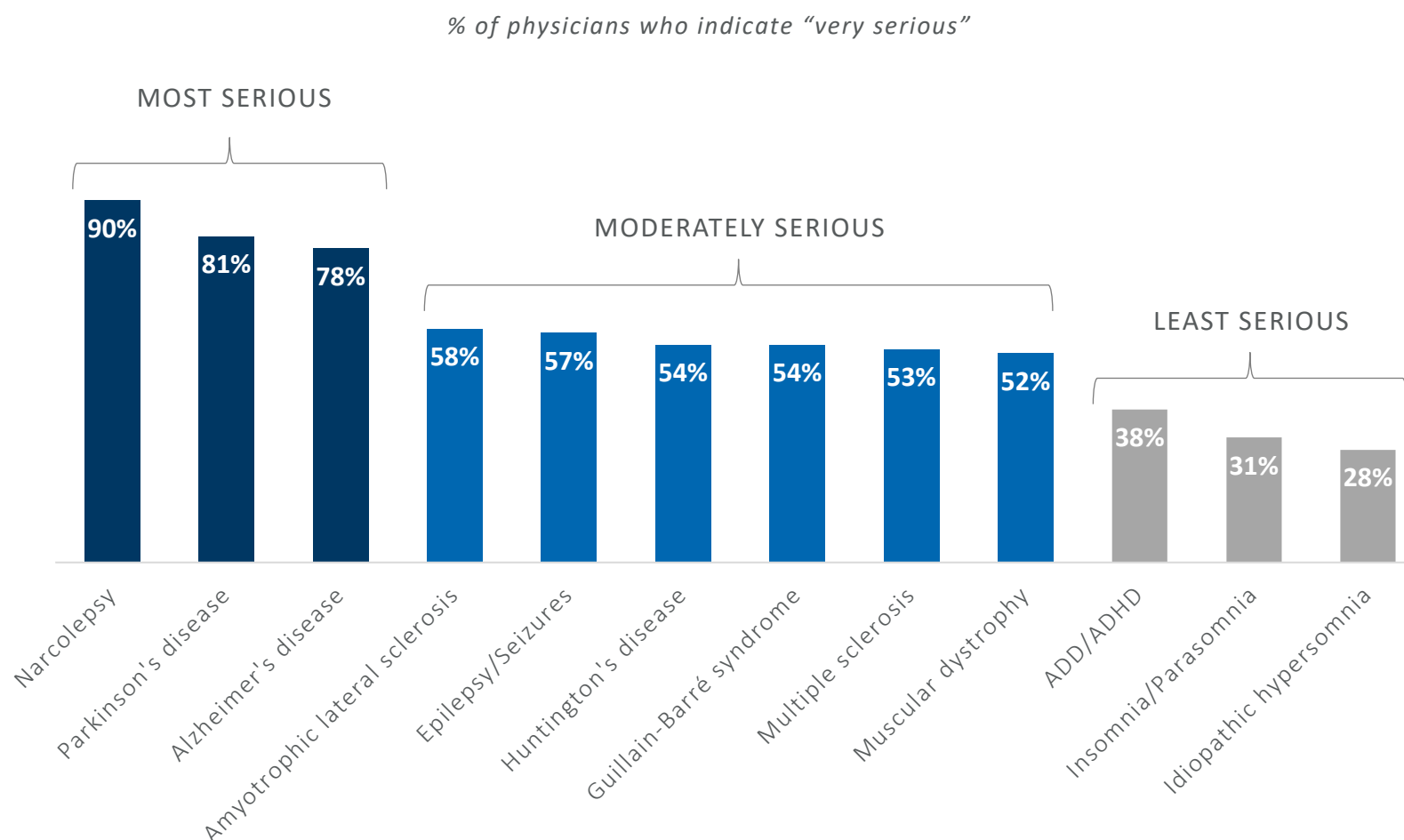
# Narcolepsy awareness is on the rise among Greater Boston area physicians

FTI’s survey reveals that the share of Greater Boston area physicians who consider themselves very knowledgeable of narcolepsy is well above the national average.<sup>1</sup> Nearly three-quarters of physicians consider themselves very knowledgeable of narcolepsy and nine-in-ten recognize the seriousness of this chronic neurological disorder.

## KNOWLEDGE OF NARCOLEPSY



## PERCEIVED SERIOUSNESS OF NEUROLOGICAL DISORDERS



Q: Prior to this survey, how knowledgeable were you of narcolepsy?

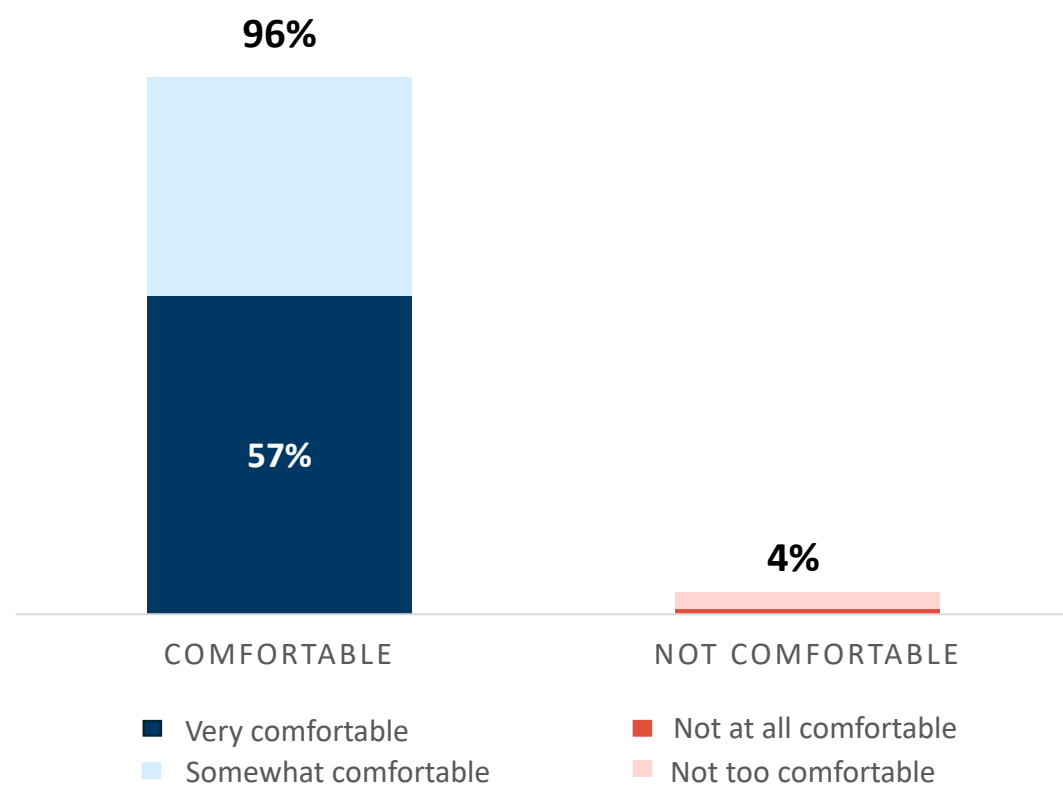
Q: In your opinion, how serious are the following neurological disorders?

Note: <sup>1</sup>In a 2012 AWAKEN survey, 62% of sleep specialists and 24% of primary care physicians considered themselves "very" or "extremely" knowledgeable about narcolepsy.

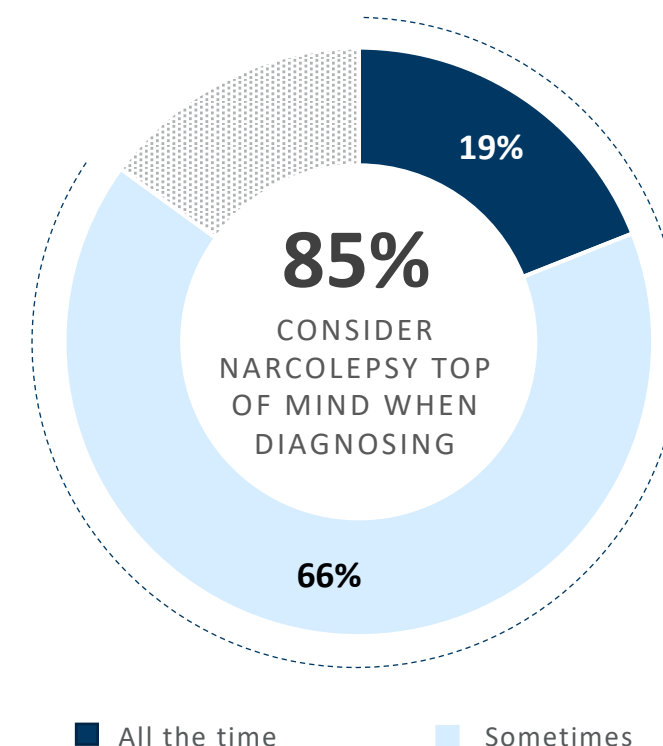
## Despite growing awareness, gaps exist when it comes diagnosing children and adolescents

The intensity of comfortability reveals physicians in the Greater Boston area lack confidence when diagnosing and treating the disorder. Just over half of physicians admit they are very comfortable diagnosing narcolepsy in children and adolescents, and only one-in-five keep narcolepsy in their mind all the time when diagnosing and treating patients.

### COMFORT LEVEL DIAGNOSING NARCOLEPSY



### EXTENT NARCOLEPSY IS “TOP OF MIND”



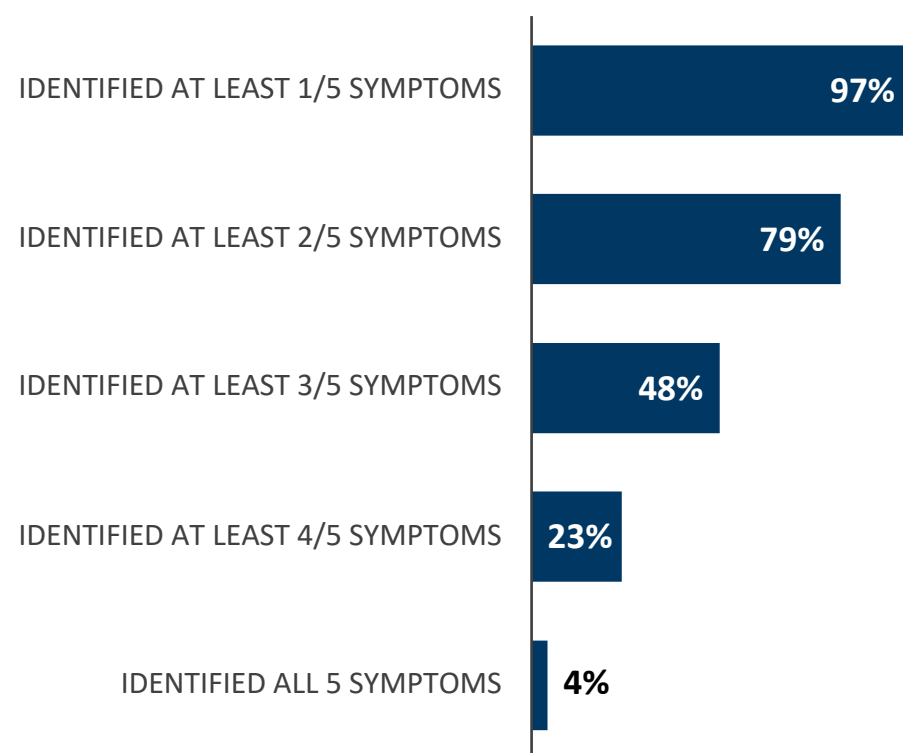
Q: To what extent do you consider narcolepsy “top of mind” when diagnosing or treating children and adolescents? Please select one response.

Q: Overall, how comfortable are you diagnosing narcolepsy in children and adolescents? Please select one response.

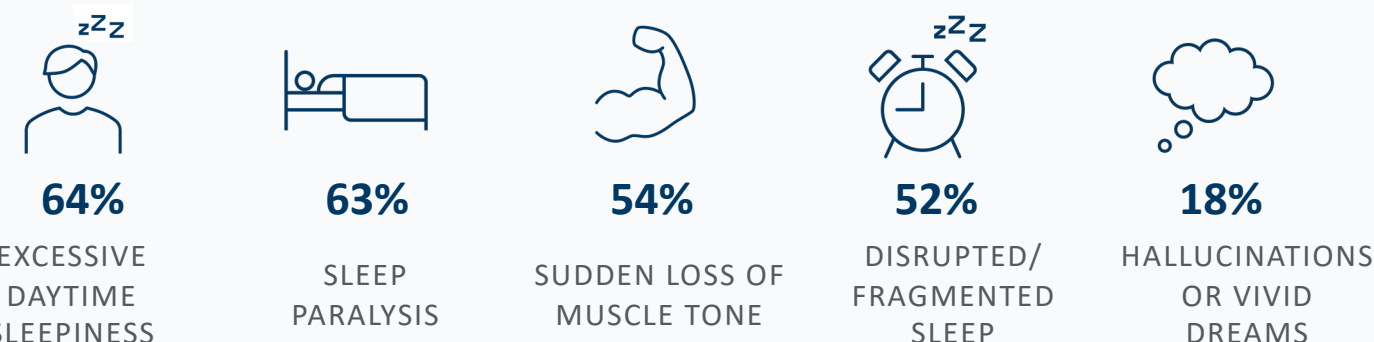
# Few physicians check for all 5 CHES<sup>1</sup> symptoms when diagnosing narcolepsy, and fewer than half know 3 or more symptoms

Excessive daytime sleepiness and sleep paralysis are the most ‘looked for’ symptoms. However, more physicians track changes in weight and trouble staying awake during the day, rather than assessing for other CHES symptoms like cataplexy, sleep disruptions, or hallucinations.

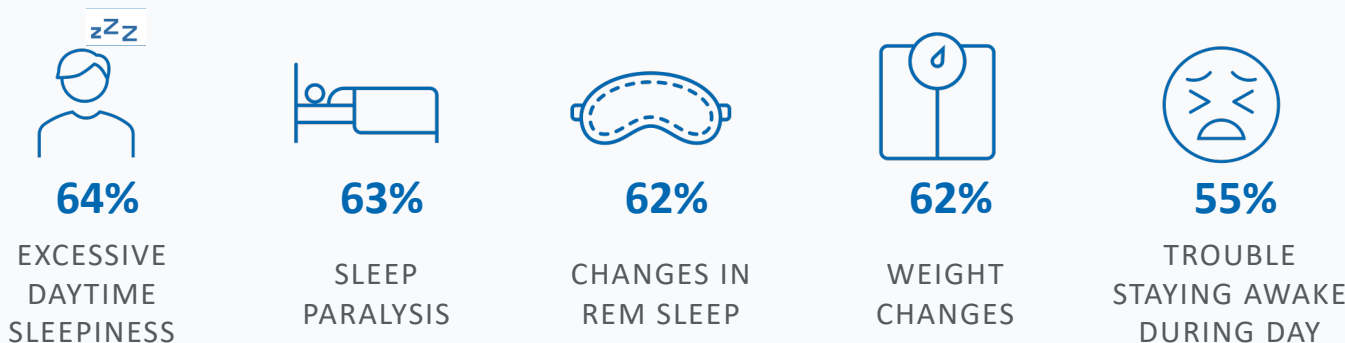
## AWARENESS OF CHES SYMPTOMS



## CHES SYMPTOMS PHYSICIANS CORRECTLY LOOK FOR



## TOP 5 SYMPTOMS PHYSICIANS LOOK FOR



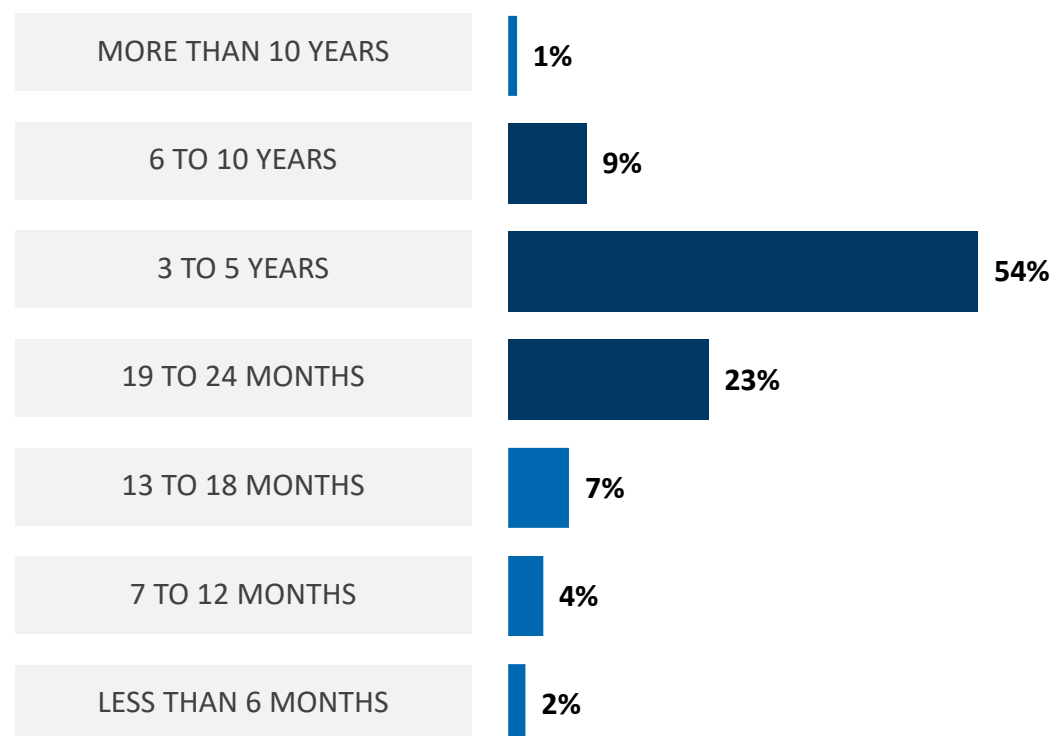
Q: Which specific symptoms, if any, do you look for in children and adolescents when considering a narcolepsy diagnosis?

Note: <sup>1</sup> There are 5 main symptoms of narcolepsy, referred to by the acronym CHES (Cataplexy, Hallucinations, Excessive daytime sleepiness, Sleep paralysis, Sleep disruption).

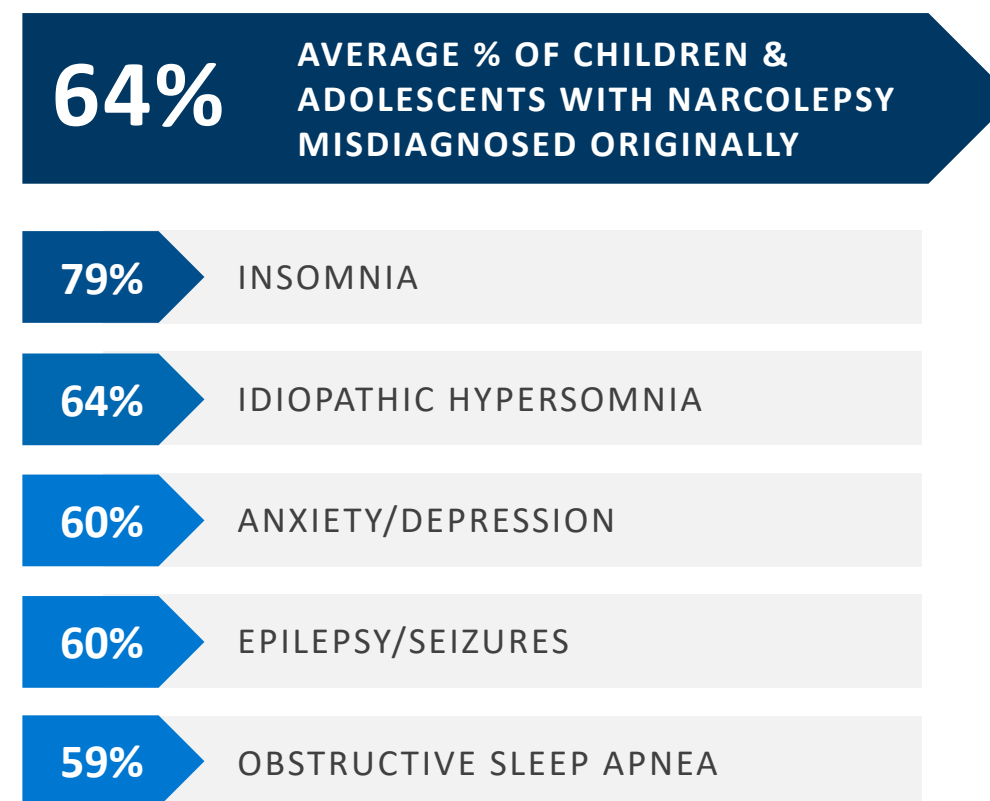
# Nearly two-in-three children and adolescents with narcolepsy get misdiagnosed

Greater Boston area physicians claim it can take anywhere from 2 to up to 10 years from patient-reported symptom onset to narcolepsy diagnosis. Insomnia, idiopathic hypersomnia, and anxiety/depression are the most reported misdiagnoses.

## TYPICAL TIME TO NARCOLEPSY DIAGNOSIS



## COMMON NARCOLEPSY MISDIAGNOSES



Q: In your experience, what is a typical time period from patient-reported symptom onset to narcolepsy diagnosis?

Q: In your experience, what percentage of children and adolescents with narcolepsy have been misdiagnosed with other disorders?

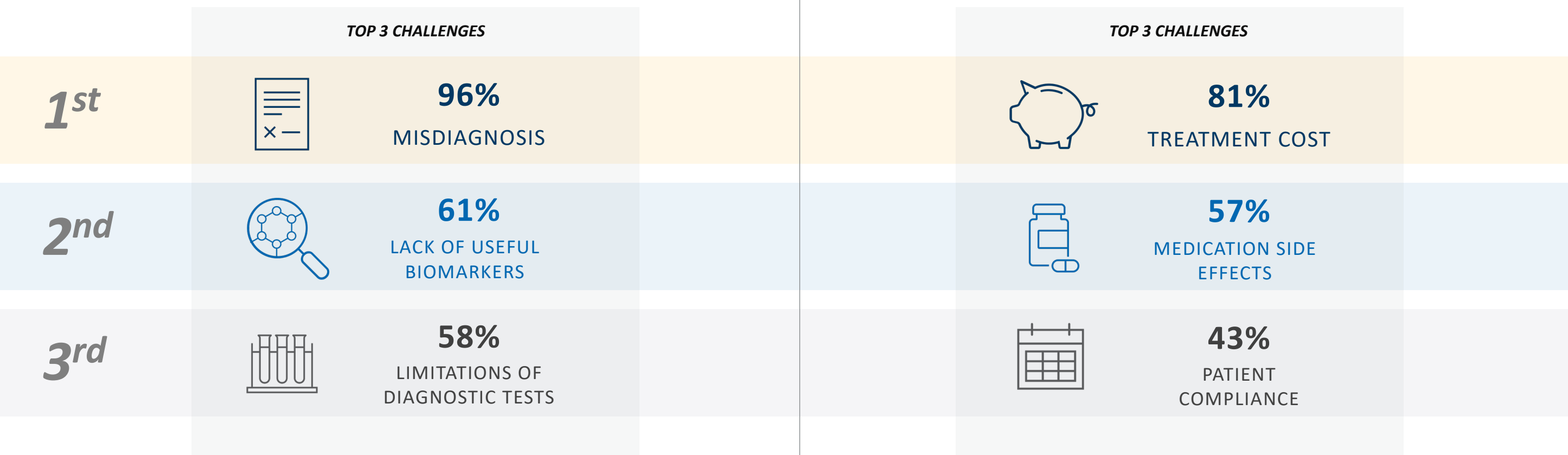
Q: Which of the following, if any, are popular disorders that children and adolescents with narcolepsy often get misdiagnosed with?

# In fact, misdiagnosis is the primary challenge when diagnosing narcolepsy

Greater Boston area physicians also report the lack of useful biomarkers and the limitations of current diagnostic tests as common challenges when diagnosing children and adolescents with narcolepsy; while the cost of treatment, treatment side effects, and patient compliance with medication are the primary struggles when prescribing treatment.

## CHALLENGES WHEN DIAGNOSING NARCOLEPSY

## CHALLENGES WHEN TREATING NARCOLEPSY



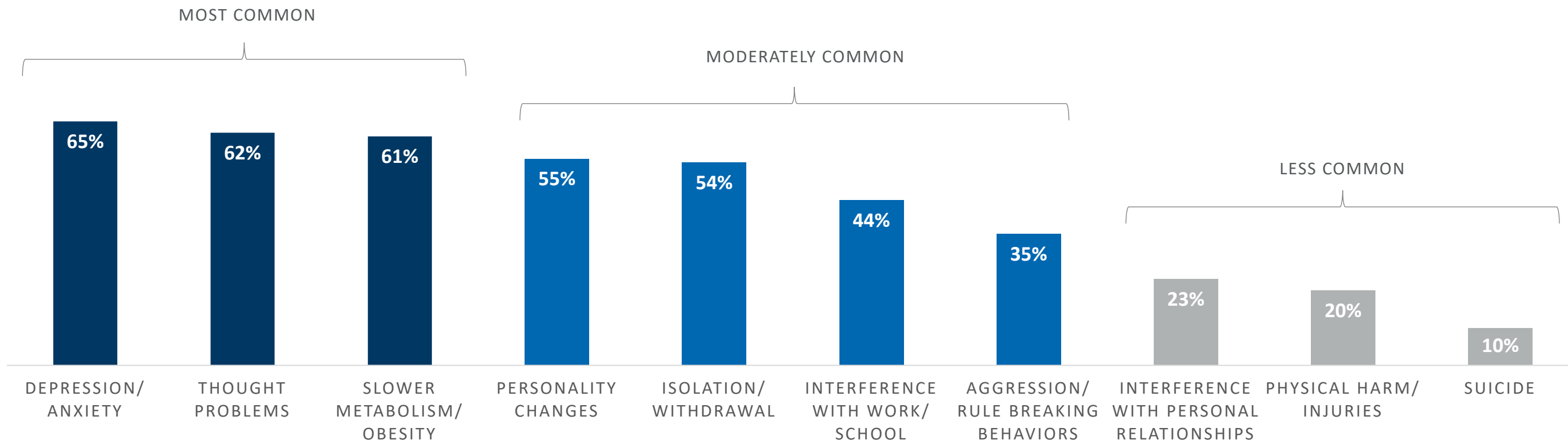
Q: What challenges, if any, do you face when diagnosing children and adolescents with narcolepsy?

Q: What challenges, if any, do you face when prescribing treatment to children and adolescents with narcolepsy?

## Nearly all physicians have witnessed narcolepsy complications in children and adolescents

Depression/anxiety, thought problems, and slower metabolism/obesity are the most common complications when dealing with narcolepsy, reported by nearly two-thirds of Greater Boston area physicians. Other frequent complications include personality changes and isolation/withdrawal.

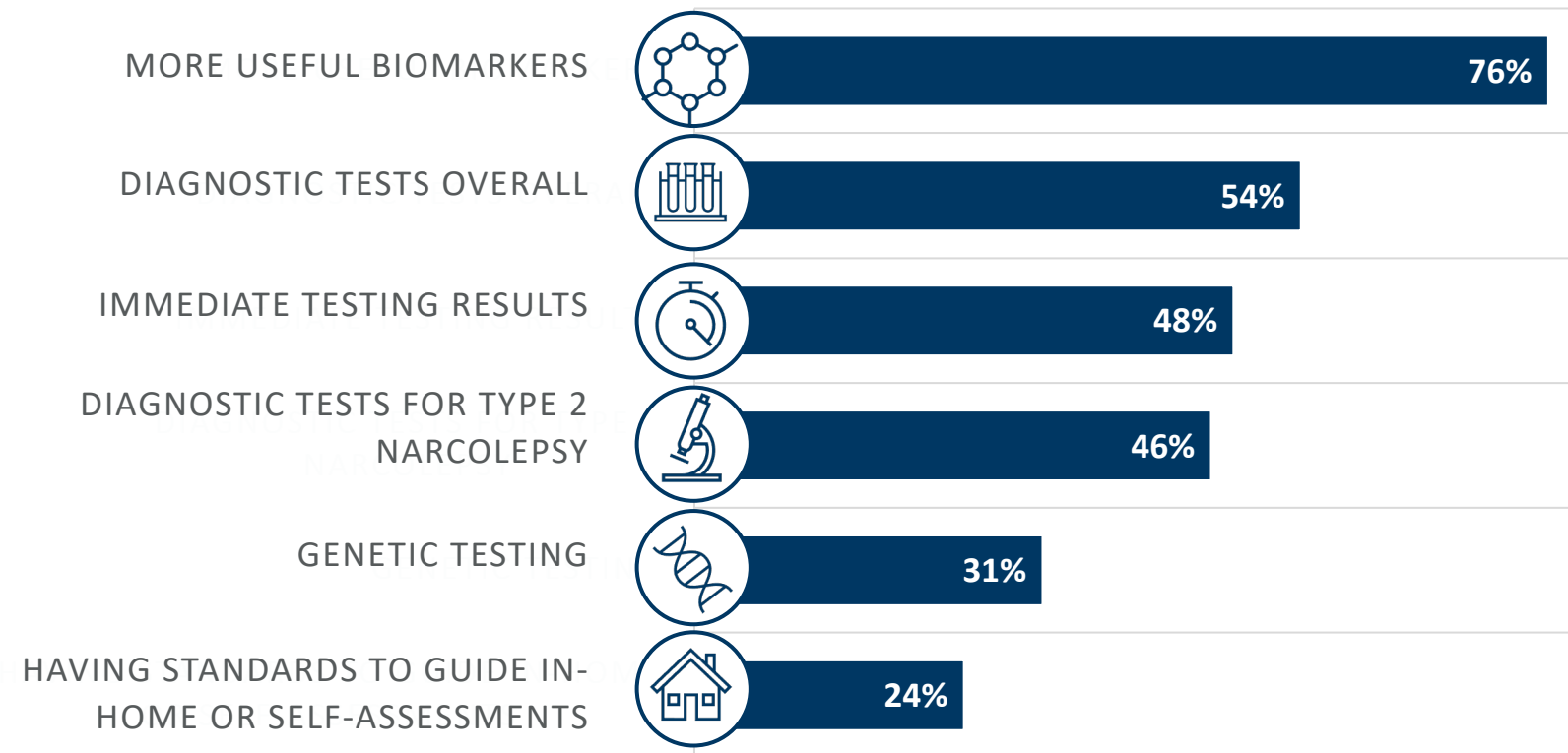
### COMPLICATIONS IN CHILDREN AND ADOLESCENTS WITH NARCOLEPSY



## Physicians say they primarily hope to see improvements in biomarkers

When asked which new efficacious diagnostic or treatment options they hope to see in the future, the majority of physicians, especially specialists, express a desire to see more useful biomarkers, followed by more effective diagnostic tests overall.

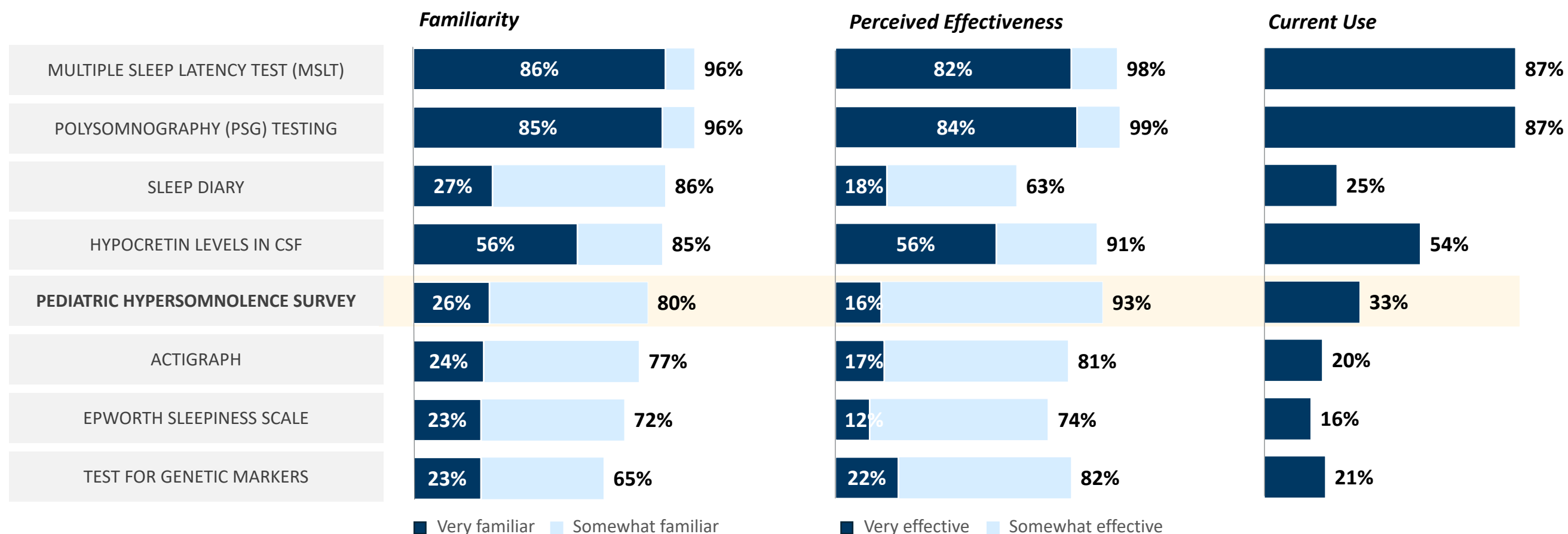
### DIAGNOSTICS AND TREATMENT EXPECTATIONS IN THE NEXT 3 YEARS



## Greater Boston area physicians have heard of PHS, but few are very familiar with the tool

MSLT and PSG are the most popular tests used to diagnose narcolepsy, followed by CSF testing. However, greater exposure to PHS and its effectiveness can help increase physician interest and adoption of the tool.

### EXPERIENCE WITH NARCOLEPSY DIAGNOSTIC METHODS



Q: How familiar are you with the following methods used to diagnose narcolepsy?

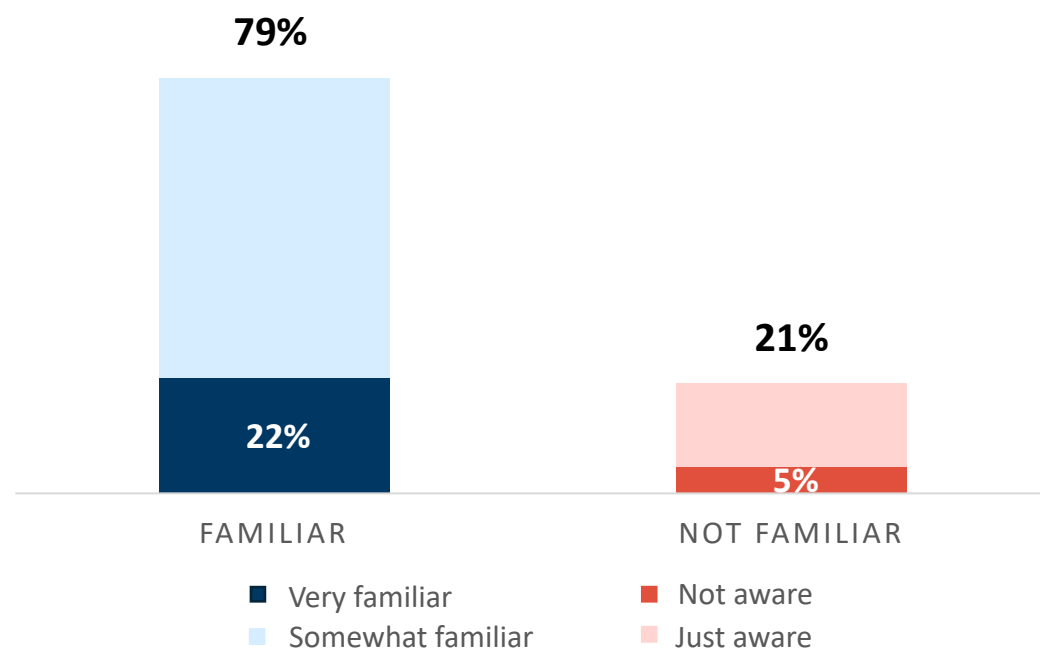
Q: How effective do you find the following methods in diagnosing narcolepsy in children and adolescents?

Q: Which of the following narcolepsy diagnostic options do you personally use to diagnose narcolepsy in children and adolescents?

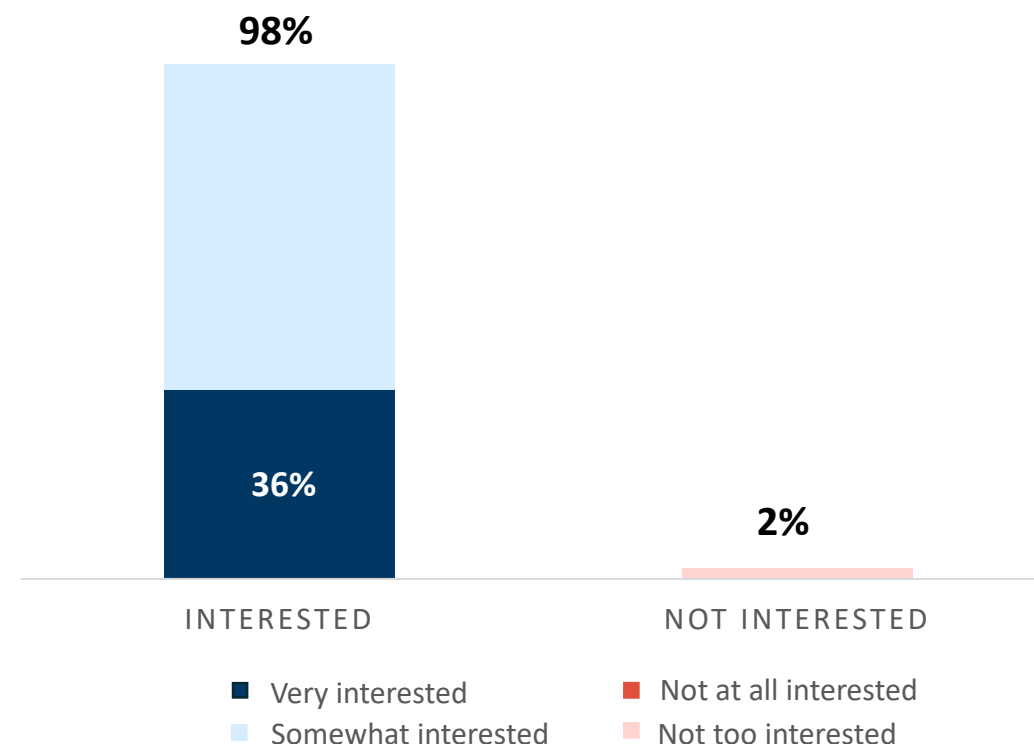
## Physicians in Greater Boston area express interest in learning more about PHS

While the majority have heard of PHS developed by Dr. Maski at Boston Children’s Hospital, around one-quarter consider themselves very familiar with the method. Most would be interested in learning more about it, including one-third who report to be very interested.

### FAMILIARITY WITH PHS DEVELOPED BY DR. MASKI



### INTEREST IN PHS DEVELOPED BY DR. MASKI



Q: Prior to this survey, how familiar were you of the Pediatric Hypersomnolence Survey developed by Dr. Kiran Maski at Boston Children’s Hospital?

Q: How interested would you be in learning more about the Pediatric Hypersomnolence Survey developed by Dr. Kiran Maski at Boston Children’s Hospital?

Q: What types of information related to narcolepsy diagnostic options, such as the Pediatric Hypersomnolence Survey developed by Dr. Kiran Maski, would you want to hear more about to help inform diagnostic decisions?



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