

Relative Prevalence of Narcolepsy Type 1, Narcolepsy Type 2, and Idiopathic Hypersomnia: A Claims Database Analysis

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INTRODUCTION

- Central disorders of hypersomnolence (CDoH), including narcolepsy type 1 (NT1), narcolepsy type 2 (NT2), and idiopathic hypersomnia (IH), are rare, chronic disorders characterized by excessive daytime sleepiness¹⁻³
- Cataplexy, which is pathognomonic for NT1, may be subtle in presentation, particularly in pediatric patients¹
 - The diagnosis of NT1 may be confirmed by lack of orexin in the cerebrospinal fluid; however, this is not routinely evaluated in clinical practice¹
- Other symptoms of these CDoH overlap, and objective testing to support the diagnosis of NT2 and IH are not reliably reproducible, causing diagnoses to change among these CDoH^{1,4}
- Prevalence estimates of these disorders vary greatly across datasets and geographic regions, with studies reporting:
 - 13-50 per 100,000 persons for NT1⁵⁻⁷
 - 25-65 per 100,000 persons for NT2^{7,8}
 - 8-37 per 100,000 persons for IH^{9,10}
- The challenges of definitive diagnoses of CDoH warrant further investigation into the relative prevalence of these disorders by using stable, nonchanging diagnoses

OBJECTIVE

- To estimate the relative frequencies of NT1, NT2, and IH in the United States and compare demographic trends among these disorders using a real-world approach, restricted to analysis of stable, nonchanging diagnoses

METHODS

DATA SOURCE AND PATIENT POPULATION

- Data from the Komodo Health claims database, comprising data from >330 million patients in the US, were used to retrospectively identify patients with NT1, NT2, or IH in 2023 (ie, ≥ 1 *International Classification of Diseases, 10th Revision* [ICD-10] diagnosis code in 2022 or 2023)
- The patient population was narrowed by defining a high-confidence diagnostic subset (**Table**)
 - High-confidence diagnosis was defined as ≥ 2 relevant ICD-10 codes for only 1 CDoH documented ≥ 30 days apart without any diagnoses of a different CDoH during the study period of 2018-2023

TABLE: Inclusion and Exclusion Criteria for High-Confidence Diagnostic Subset

Inclusion criteria	Exclusion criterion
100% claim availability for 6 consecutive years (2018-2023) ≥ 2 claims documented ≥ 30 days apart with a relevant ICD-10 code - NT1: G47.411, G47.421 - NT2: G47.419, G47.429 - IH: G47.11, G47.12	Multiple distinct diagnoses of NT1, NT2, and IH

ICD-10, *International Classification of Diseases, 10th Revision*; IH, idiopathic hypersomnia; NT1, narcolepsy type 1; NT2, narcolepsy type 2.

DATA ANALYSIS

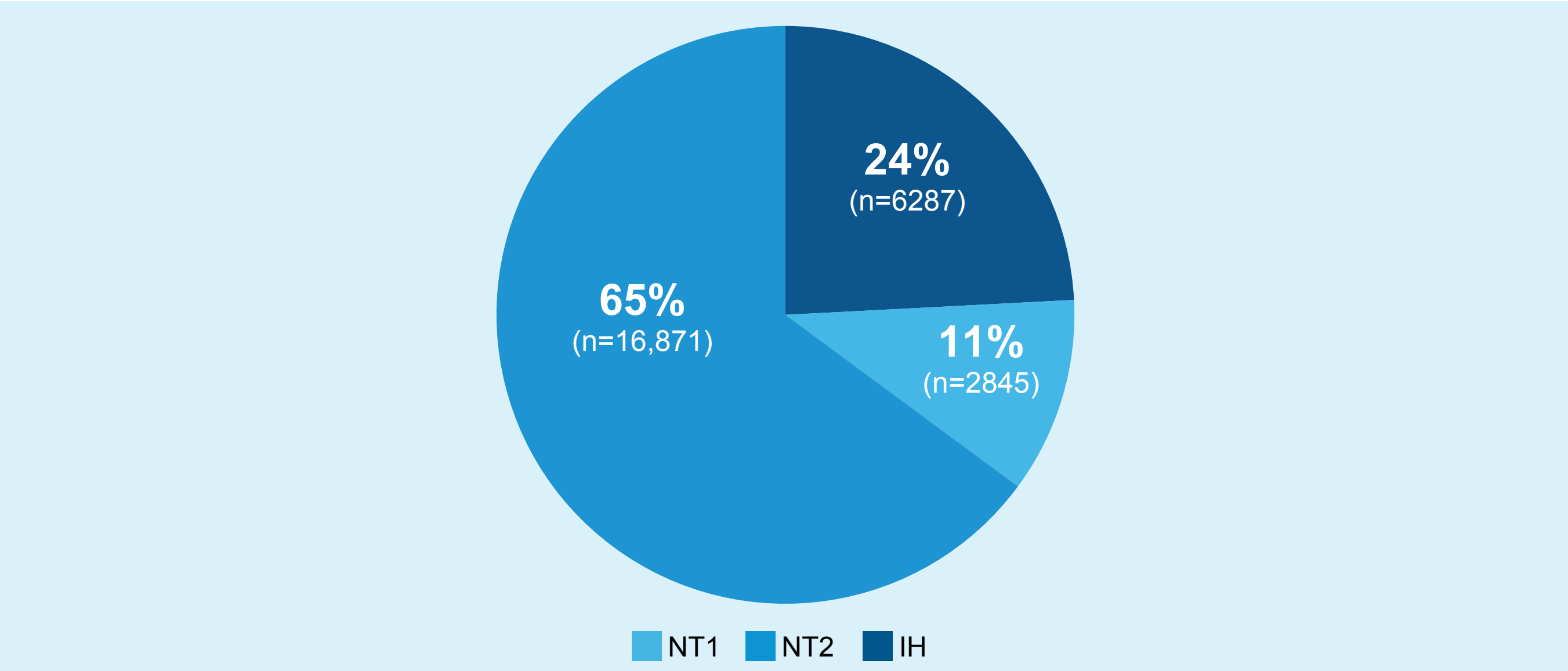
- The number (%) of patients was calculated for diagnosis, sex, and age group
- Data were analyzed descriptively

RESULTS

PREVALENCE OF NT1, NT2, AND IH

- Of 154,750 patients with ≥ 1 NT1, NT2, or IH diagnosis in 2023 included from the Komodo claims dataset, 39,789 (26%) had all claims data available within the 2018-2023 study period and the majority (n=102,040 [66%]) had only 1 CDoH diagnosis
 - 26,003 patients were identified as having the highest confidence diagnosis and were included in this analysis
- The majority of patients in this dataset were diagnosed with NT2 (**Figure 1**)

FIGURE 1: Prevalence of Diagnoses



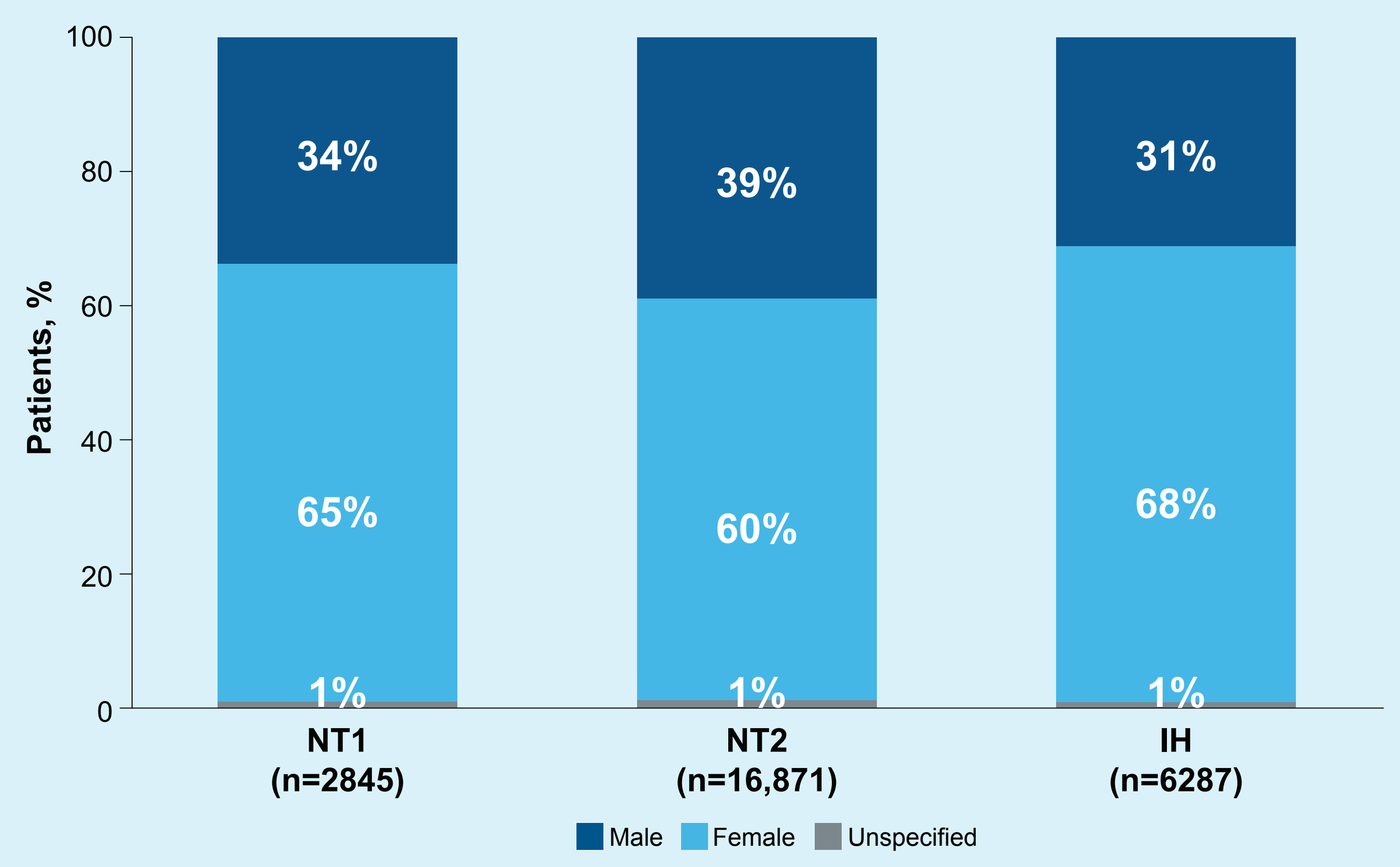
IH, idiopathic hypersomnia; NT1, narcolepsy type 1; NT2, narcolepsy type 2.

- The prevalence of NT1, NT2, and IH was 9.4, 29.1, and 9.7 per 100,000 persons, respectively

PATIENT CHARACTERISTICS

- The ratio of female to male patients was nearly 2:1 across all diagnoses (**Figure 2**; overall: female, n=16,236 [62%]; male, n=9482 [36%]; unspecified, n=285 [1%])

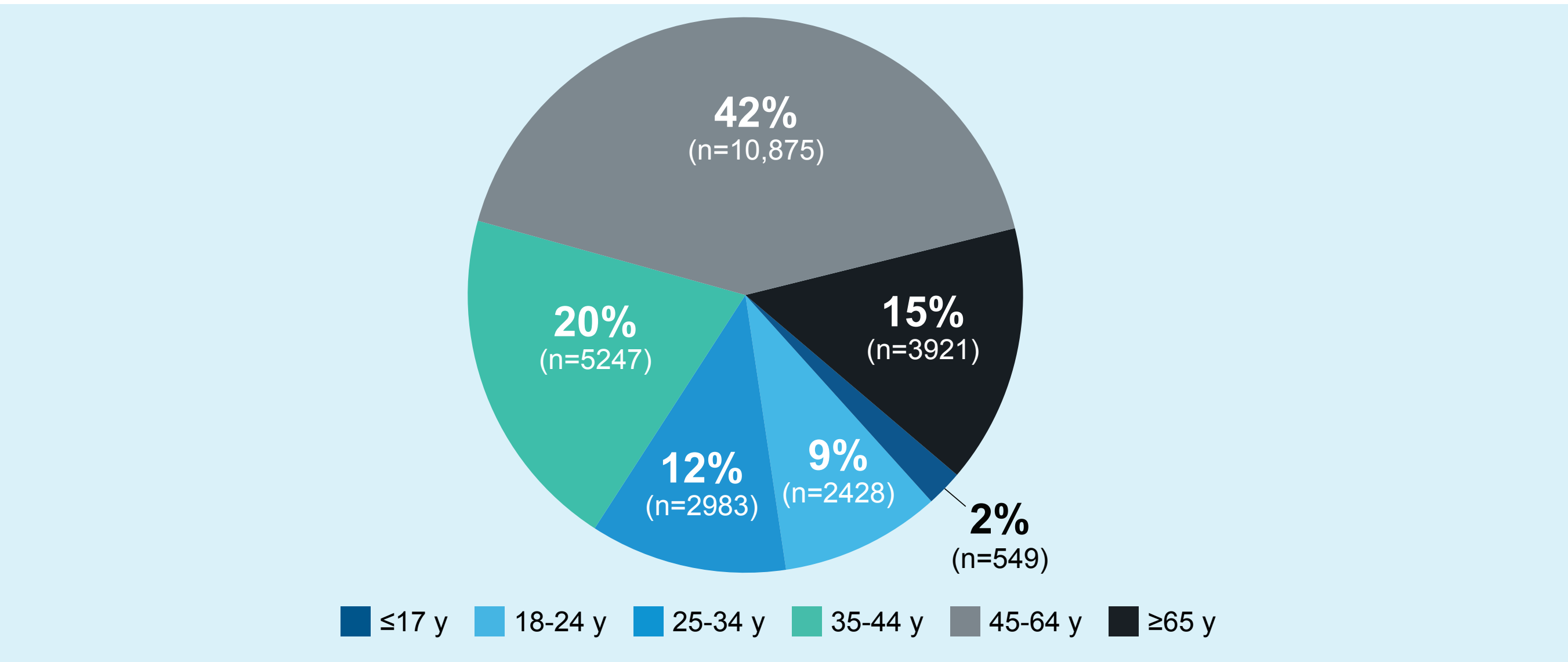
FIGURE 2: Sex Distribution Across Diagnoses



IH, idiopathic hypersomnia; NT1, narcolepsy type 1; NT2, narcolepsy type 2.

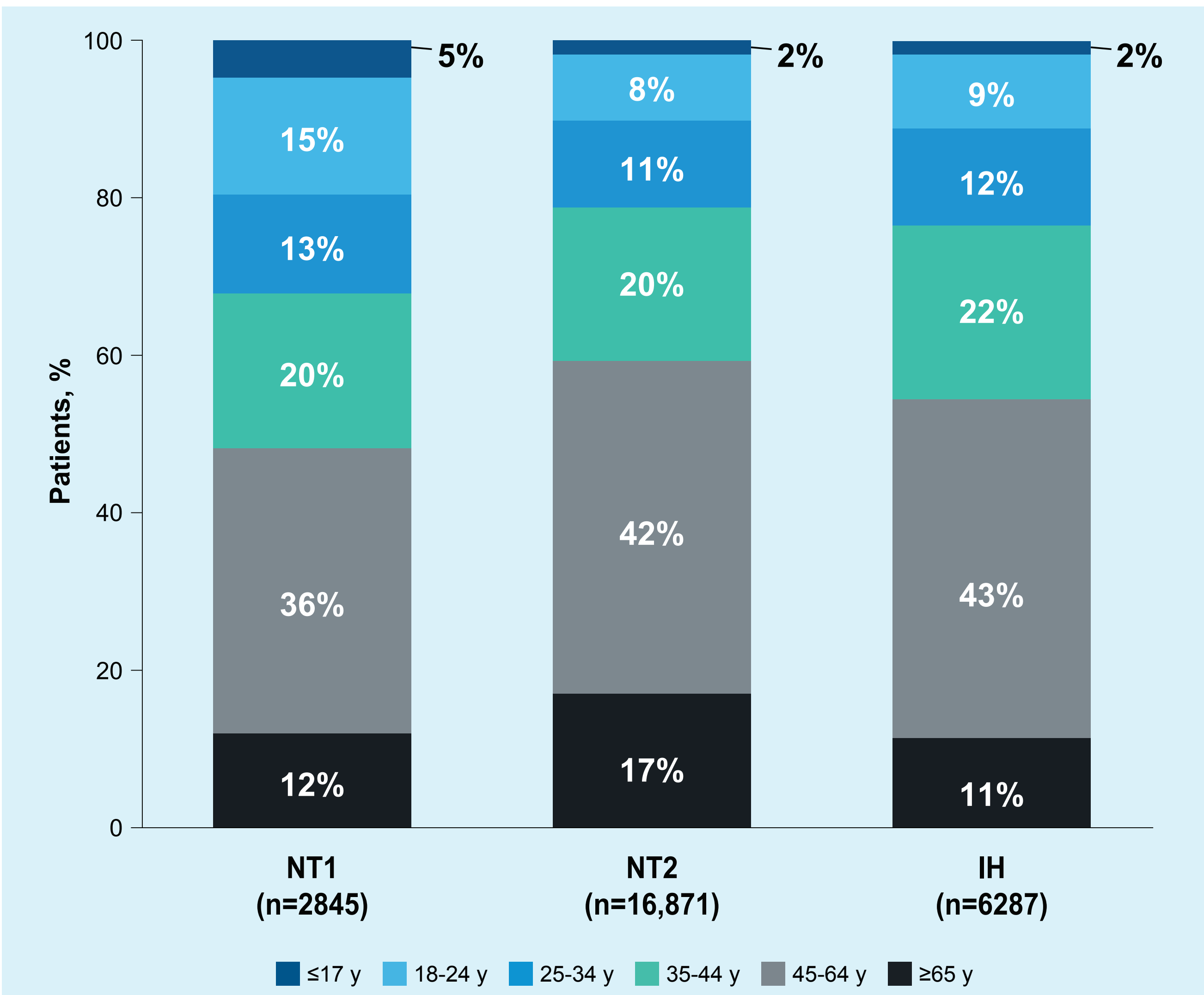
- Overall, approximately 75% of patients were ≥ 35 years of age (**Figure 3**)

FIGURE 3: Overall Age Distribution



- Across all diagnoses, a greater proportion of the patients were ≥ 35 years of age (**Figure 4**)

FIGURE 4: Age Distribution Across Diagnoses



IH, idiopathic hypersomnia; NT1, narcolepsy type 1; NT2, narcolepsy type 2.

STUDY LIMITATIONS

- Given the limitations of available clinical information in claims database analyses, these data should be interpreted with caution
 - As with any claims-based analysis, billing data may lack clinical detail and contain coding errors that can lead to bias outcome estimates and limit generalizability
 - The requirement for a stable diagnosis likely underestimates the NT1 cohort by excluding patients whose cataplexy may not be present at initial diagnosis or worsens over time
 - Limitations of objective tests, including polysomnography and multiple sleep latency testing in NT2 and IH, underscore the need to prioritize patient-reported clinical assessments (eg, Epworth Sleepiness Scale, Narcolepsy Severity Scale, or Idiopathic Hypersomnia Severity Scale) for diagnosis of CDoH

CONCLUSIONS

- In this study, NT2 was diagnosed approximately 6 times more frequently than NT1 and nearly 3 times more frequently than IH
- Prevalence estimates in this analysis differ from prior reports; this could reflect the requirement for a stable diagnosis
- Excluding patients with uncertain diagnoses provides a complementary perspective to previously published data when assessing the relative frequencies of CDoH

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DISCLOSURES

RB has served as a consultant, speaker, and/or on advisory boards for Avadel Pharmaceuticals, Harmony Biosciences, and Jazz Pharmaceuticals. MJT has served as a consultant or on advisory boards for Avadel Pharmaceuticals, Axxone Therapeutics, Balance Therapeutics, Eisai, Harmony Biosciences, Jazz Pharmaceuticals, NLS Pharmaceuticals, Suvon Life Sciences Ltd, and Takeda Pharmaceutical Co. SDM has received funding for conducting research studies from Alkermes, Inc., Avadel Pharmaceuticals, Axxone Therapeutics, and Jazz Pharmaceuticals and has served on an advisory board for Avadel Pharmaceuticals. MCA has served as a consultant, speaker, and/or on advisory boards for Axxone Therapeutics, Avadel Pharmaceuticals, and Jazz Pharmaceuticals. AMM has served as an investigator, consultant, speaker, and/or on advisory boards for Alkermes, Inc., Aptivmed, Avadel Pharmaceuticals, Axxone Therapeutics, Eisai, Harmony Biosciences, Jazz Pharmaceuticals, Lilly, Nobe Pharmaceuticals, Novartis, and Takeda Pharmaceutical Co. has received grant funding from the National Institutes of Health, UCB Pharmaceuticals, Jazz Pharmaceuticals, ResMed Foundation, Covens Community Healthcare Foundation, Harmony Biosciences, and Geisinger Health Plan. is the Chief Executive Officer of DAMM Good Sleep, LLC, and serves as an advisor for Neura Health, OpenEvidence, and FloraWorks. JG was an employee of Avadel Pharmaceuticals and is a consultant to Alkermes, Inc. BA is an employee of Alkermes, Inc.

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