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Prevalence of Thyroid Eye Disease (TED) in the United States

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BACKGROUND

- Accurate population-level data on the prevalence of TED in the United States is limited, impeding a clear understanding of disease burden

OBJECTIVES

1. Estimate the prevalence of patients diagnosed and actively managed with TED in the US using real-world data (RWD)
2. Analyze the incidence rates by patient characteristics, including age and gender

METHODS

- We conducted 2 separate retrospective, observational studies using Forian open and closed claims data.* Patients were included in the analysis if they had a Graves' disease diagnosis code on ≥2 medical claims (ICD-10 codes E05.00 or E05.01) at least 180 days apart between January 2017 and December 2023 or ≥1 medical claims for teprotumumab
- Two patient cohorts were used for this analysis with differing levels of strictness
  - TED Criteria: Required that patients received a medical claim submitted by an ophthalmologist for a TED-related diagnosis code, imaging claims related to TED, or teprotumumab use
  - Vision Threatening Manifestation (VTM) Criteria: Based on a prior study that examined the management of a subset of TED patients with dysthyroid optic neuropathy and corneal disease[1]
- Incidence rates were calculated using both open and closed claims data and projected to national estimates using US census data stratified by age, gender, and state (open claims) or total enrolled patients on an annualized basis (closed claims)

*All data contained in the information products licensed from Forian Inc. are de-identified in compliance with the Health Insurance Portability and Accountability Act of 1996, as amended, together with the regulations promulgated thereunder ("HIPAA"), as certified by the determination of a qualified expert in accordance with Section §164.514(b)(1) of the HIPAA Privacy Rule.

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RESULTS

TED patients were identified in the claims data by relevant TED-related diagnosis or procedure codes.

	Raw Patient Counts	Projected Patients
Patients with a medical claim for E05.00 or E05.01 or teprotumumab from 2017 to 2023	230,568	
2+ medical claims ≥180 days apart or teprotumumab	120,891	
Medical claim from an ophthalmology practice	49,752	
Medical claim for a TED-related visit	29,016	178,822
Medical claim for VTM	20,727	148,192

Table 1. Patient Identification Criteria for TED Cohort (Closed Claims). Stepwise application of inclusion criteria used to identify patients with TED. Narrowing to those with confirmed broader TED-related ophthalmology visits (TED criteria) and visits with diagnosis codes for more severe VTMs (VTM criteria).

TED cases rose over time, with over 80% of patients being female and an average age approaching 48.

Year	TED Patients	Enrolled Patients	Prev per 100K	Female, %	Age, mean
2017	5,800	43,605,606	13	82%	47.2
2018	6,839	44,574,581	15	82%	47.6
2019	7,156	44,710,758	16	82%	47.3
2020	8,032	45,060,536	18	81%	47.8
2021	9,467	46,079,919	21	82%	48.0
2022	9,978	46,742,651	21	81%	48.0
2023	9,524	47,088,337	20	82%	48.4

Table 2. TED Patient Demographics and Point Prevalence by Year (Closed Claims). Prevalence for TED patients, active in a given year, was calculated per 100,000 individuals based on enrolled patients in the closed claims dataset for a given year.

TED patient demographics by age group show consistent trends over the past 7 years.

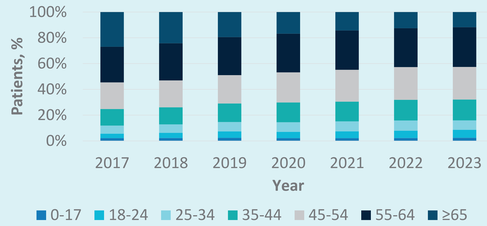

Figure 1. Patient Population by Age Group (Closed Claims). This chart illustrates the proportion of patients within different age groups for closed claims from 2017 to 2023. Percentages are calculated based on the total number of patients in each respective year.

Analysis of both open and closed claims datasets demonstrated that active TED patients in 2023 ranged from 43,539 to 100,474.

Claims Source	Definition	Prevalence per 100K, 2023	Projected 2023 Census Population
Closed	VTM, projected	13	43,539
Closed	TED, projected	20	66,983
Open	VTM, projected	24	80,380
Open	TED, projected	30	100,474

Table 3. Point Prevalence and Census Estimates for TED Patients in 2023. Prevalence in open and closed claims data was calculated in 2023 based on both VTM and TED definitions. Patients in open claims data were projected based on total patients in open data set in 2023. Patients in closed claims were projected based on enrolled patient in 2023 in the closed data set.

LIMITATIONS

- Younger patients with TED are less likely to require active management, due to less fibrotic disease and may be underrepresented in the analysis

CONCLUSIONS

- The estimated prevalence of actively managed TED in this study is in line with the lower end of previously published figures for the US population
  - A similarly structured claims analysis found an annual prevalence of 19 per 100,000 patients of all ages[2]
  - A study of ophthalmology electronic medical records demonstrated an overall prevalence of 90 per 100,000 in adult patients[1]
  - Classic epidemiologic data suggest an age-adjusted incidence rate of 16.0 cases per 100,000 population per year for females and 2.9 cases per 100,000 population for males[3]

DISCLOSURES

- John Walsh, Cathy Andorfer, and Kristine Erickson: employed by Tourmaline Bio Inc. and financial interest from Tourmaline Bio Inc.
- Alon Kahana: consultant/contractor for BioTissue, Inc.; patent with Fred Hutchinson Cancer Research Center, University of Michigan; recipient from Fred Hutchinson Cancer Research Center; research funding from Tourmaline, Sling, Viridian, Acelyrin, Immunovant, Lassen, Kriya
- Roger Turbin: consultant/contractor for Horizon Therapeutics, Viridian Therapeutics, Inc.; financial support from Horizon Therapeutics, Medtronic (expired), Viridian Therapeutics, Inc.; financial interest from Viridian Therapeutics, Inc.
- Daniel Leszkiewicz, Robert Gabruk, and Mark Scott Brown: Nothing to disclose

MORE INFORMATION

To **learn more**, visit: **www.tourmalinebio.com**

We are currently recruiting for:
A Study to Investigate Efficacy and Safety of TOUR006 in Participants 18 to 80 Years of Age With Thyroid Eye Disease (spiriTED)
For **study details**, visit:
www.clinicaltrials.gov/study/NCT06088979

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REFERENCES: 1. Ramesh S et al. *Am J Ophthalmol*. 2023;253:74-85. 2. Chen X et al. Presented at: American Thyroid Association Annual Meeting; September 27-October 1, 2023; Washington, DC. 3. Bartley GB. *Trans Am Ophthalmol Soc*. 1994;92:477-588.

FOOTNOTES: TED criteria included medical claims for the following ICD-10 codes. VTM criteria included those with asterisks: E05.00, E05.01, E05.10, E05.20, E05.30, E05.40, E05.80, E05.81, E05.90, E05.91, H02.531, H02.532, H02.533, H02.534, H02.535, H02.536, H02.539, H02.841, H02.842, H02.843, H02.844, H02.845, H02.846, H02.849, H05.20, H05.221, H05.222, H05.223, H05.229, H05.241, H05.242, H05.243, H05.249, H05.821, H05.822, H05.823, H05.829, H16.8,* H46.8, H46.9, H47.01,* H47.011,* H47.012,* H47.013,* H47.019,* H47.20, H47.211, H47.212, H47.213, H47.231, H47.232, H47.233, H47.239, H47.291, H47.292, H47 293, H47.299, H49.881, H49.882, H49.883, H49.9, H50.00, H50.011, H50.012, H50.021, H50.022, H50.041, H50.042, H50.05, H50.06, H50.07, H50.08, H50.10, H50.111, H50.112, H50.131, H50.15, H50.16, H50.17, H50 18, H50 21, H50 22, H50 30, H50.311, H50.312, H50.32, H50.331, H50.332, H50.34, H50.40, H50.411, H50.412, H50.42, H50.43, H50.50, H50.51, H50.52, H50.53, H50.60, H50.611, H50.612, H50.632, H50.651, H50.69, H50.811, H50.812, H50.89, H50.9, H57.89.
TED Criteria also included medical claims with the following procedure codes: J3241, 67311, 67312, 67314, 67316, 67332, 67335, 67414, 67445, 67911, 70480, 70481, 70542, 70543.