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Trends in Thyroid Eye Disease incidence and prevalence in France, 2019-2023: a nationwide population study

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Conflicts of Interest

B.M., I.G. and M.G. are Amgen SAS employees and own stock from AMGEN. S.B. is employee of Heva, the consulting company contracted by Amgen to conduct the study. B.B., P.L., and T.C. served as consultants to Amgen and contributed to the study development, data interpretation, and communication development. The authors declare no other conflicts of interest related to this work.

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Context

Thyroid eye disease (TED)

Autoimmune orbital disease that affects orbital tissues occurring in 25% to 40% of patients with Graves' disease [1]

Challenge of moderate-to-severe forms, rare but potentially leading to visual impairment

Estimated incidence of approximately 5 per 100,000 individuals in Europe [2]

Evolving therapeutic landscape with recent European recommendation update. [1, 3] and emerging targeted therapies and anticipated guideline updates

Major clinical, healthcare resource utilization, and economic burden

Scarce European real-world epidemiological data and absence of nationwide data from France

1. *Singh I, Hershman JM. Pathogenesis of Hyperthyroidism. In: Comprehensive Physiology [Internet]. John Wiley & Sons, Ltd; 2016 p. 67-79.*
2. *Boulakh L, Nygaard B, Bek T, Faber J, Heegaard S, Toft PB, et al. Nationwide Incidence of Thyroid Eye Disease and Cumulative Incidence of Strabismus and Surgical Interventions in Denmark. JAMA Ophthalmol. 1 juill 2022;140(7):667. doi:10.1001/jamaophthalmol.2022.1002.*
3. *Burch HB, Perros P, Bednarczuk T, Cooper DS, Dolman PJ, Leung AM, et al. Management of thyroid eye disease: a Consensus Statement by the American Thyroid Association and the European Thyroid Association. Eur Thyroid 2022;11:e220189.*

Objectives

1

To estimate the incidence and prevalence of patients with TED treated in hospital settings in France and assess temporal trends using newly developed identification methods

2

To characterize the sociodemographic and medical profiles of patients diagnosed with TED

3

To describe real-life treatment patterns following TED diagnosis

Data source: The French National Hospital discharge database (PMSI)

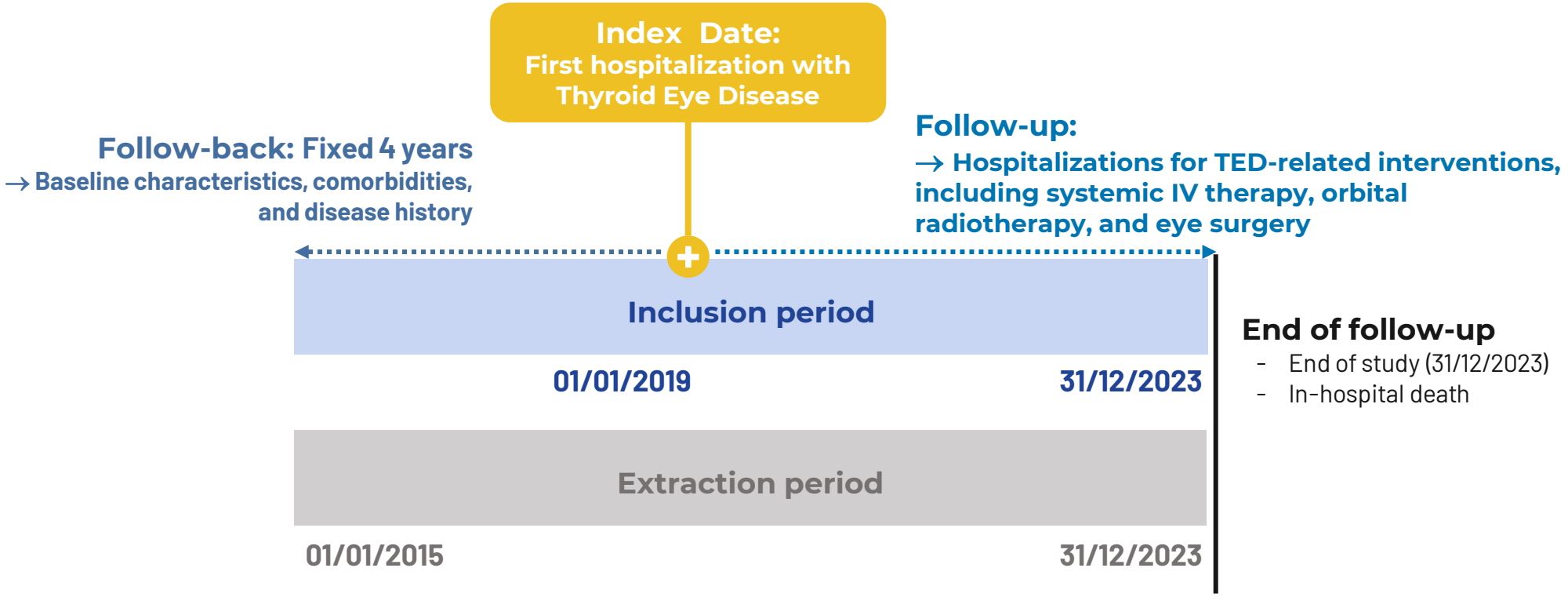
The PMSI-MCO is an exhaustive medico-administrative hospital discharge database which covers all short time hospitalizations in the public and private sectors involving short-term stays in medical, surgical or obstetric facilities, representing all day care and inpatient stays in France .

Methods

Study design

SIGHt study:

Nationwide real-world retrospective cohort study based on secondary data from the French hospital discharge database (PMSI)



Methods

Study population: implementation of two complementary identification algorithms

Specific algorithm
(Lower bound)

Restricted diagnosis codes

Ophthalmic symptoms	ICD-10 code
Dysthyroid proptosis	H06.2

Dysthyroidism	ICD-10 code
Graves' disease	E05.0

Algorithm:
One ICD-10 code of dysthyroidism **AND** one ICD-10 code of ophthalmic symptom within the same stay

Sensitive algorithm
(Upper bound)

Broader diagnosis codes

Ophthalmic symptoms	ICD-10 code
Proptosis	H06.2; H05
Diplopia	H53.2
Palpebral atrophy	H02.5
Strabismus	H49; H50
Corneal damage	H16.0; H16.3
Optical nevritis	H46
Other	H58.8; H06.3

Dysthyroidism	ICD-10 code
Graves' disease	E05.0
Thyrotoxicosis	E05 (excluding E05.0)
Autoimmune thyroiditis	E06.3

(ICD-10: International classification of disease tenth revision)

Results

Number of prevalent and incident patients

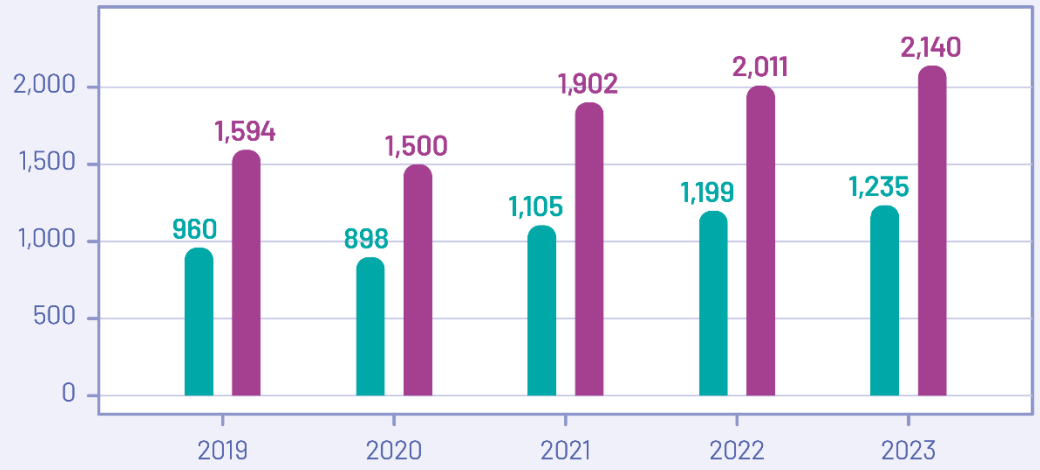
Definition:
- Prevalent patients: patients hospitalized with TED between 2019 and 2023 (at least one stay)
- Incident patients: patients hospitalized with TED between 2019 and 2023 (at least one stay) without any hospitalization with TED in the 4 years prior to index date

Prevalent patients

Specific algorithm
(Lower bound)
N= 4,063

Sensitive algorithm
(Upper bound)
N= 6,821

Annual number of prevalent hospitalized patients with TED



Patients with at least one TED hospitalization during the follow-back period

Specific algorithm

Sensitive algorithm

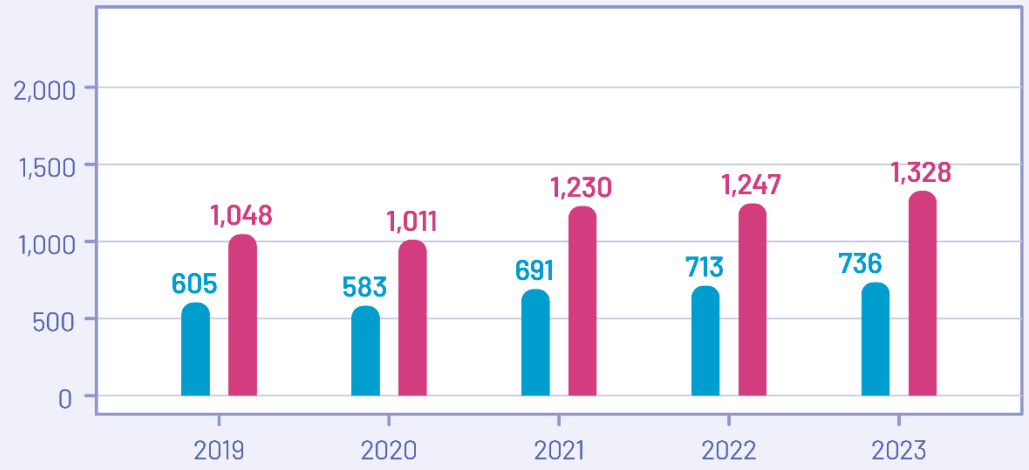
Incident patients

Specific algorithm
(Lower bound)
N= 3,328

Sensitive algorithm
(Upper bound)
N= 5,864

Incident patients with at least one year of follow-up
N= 4,422 (75.4%)

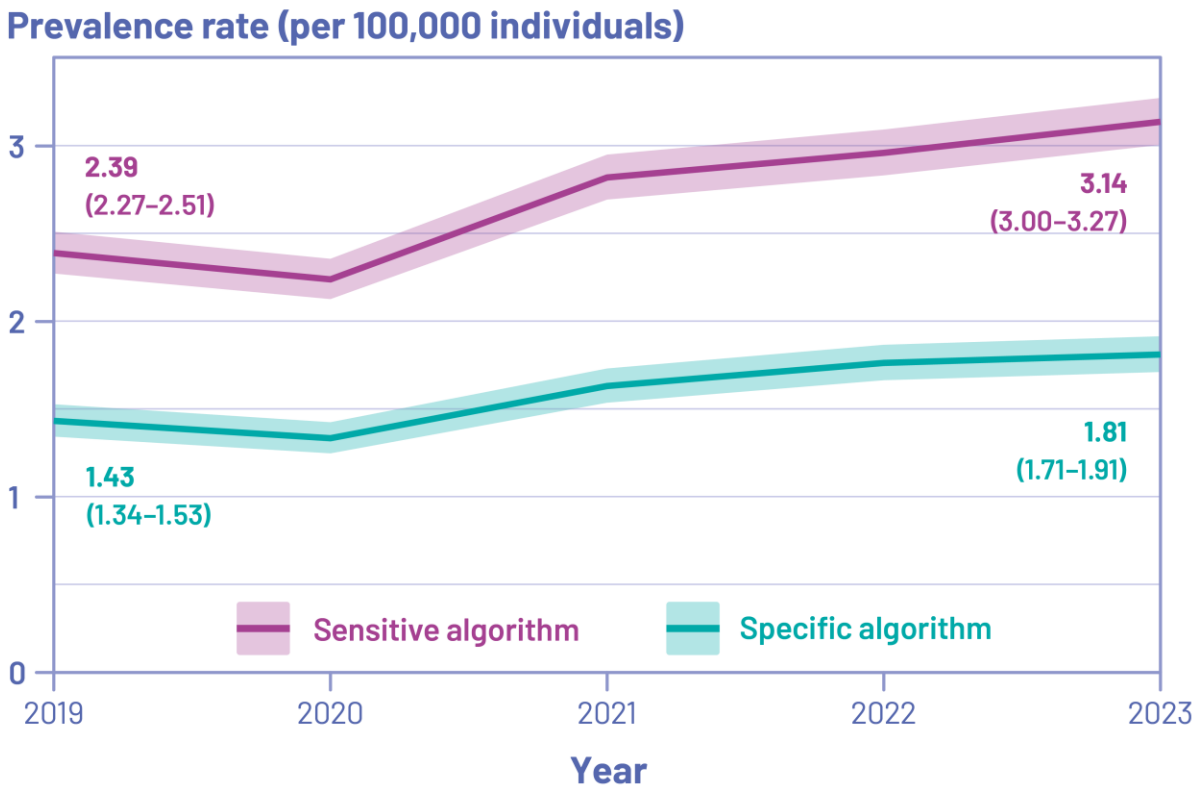
Annual number of Incident hospitalized patients with TED

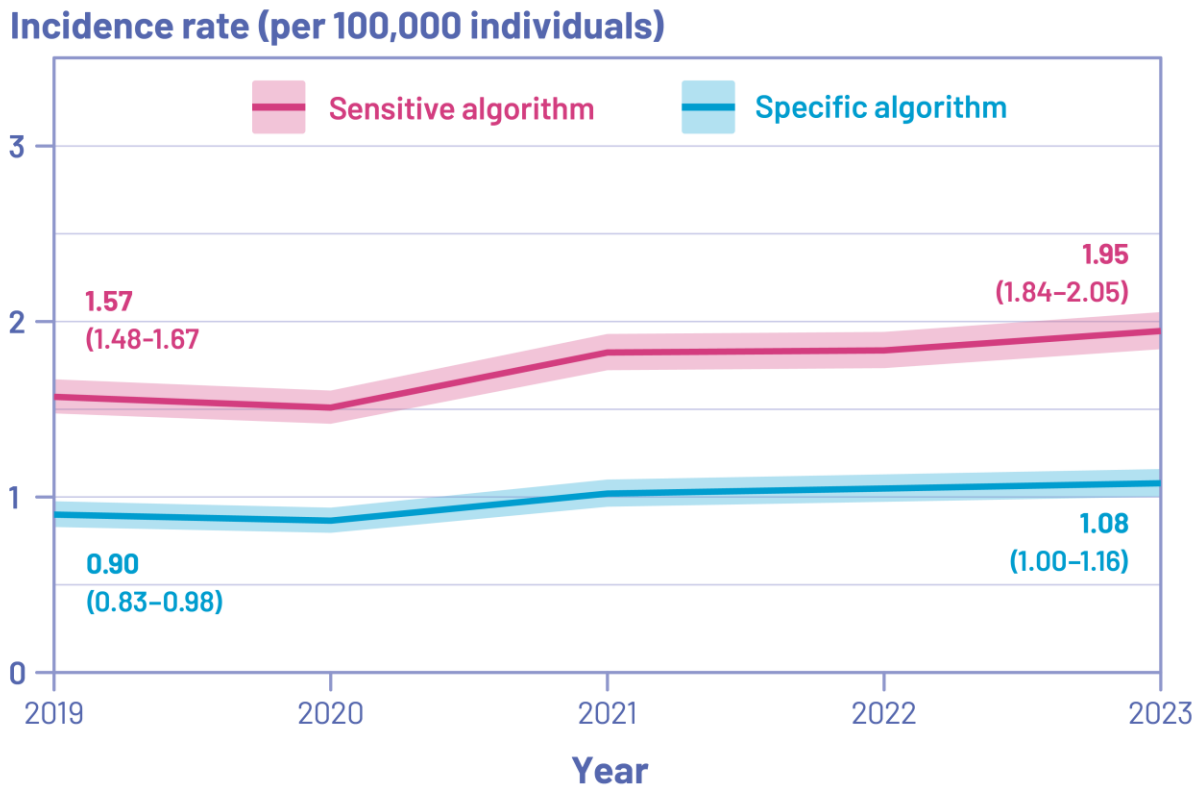


Results

Incidence and prevalence

Standardized incidence and prevalence rates





(Estimated per year with exact 95% confidence intervals)

Results

Patients' characteristics and ophthalmic symptoms at index stay

Incident population - Sensitive algorithm (Upper bound) (N = 5,864)

Patients' characteristics

Socio-demographics characteristics	Age in years, median (IQR)	54.0 (42.0-64.0)
	Female, N (%)	4,395 (74.9%)
	Smoking status	423 (7.2%)
Comorbidities N (%)	Diabetes	363 (6.2%)
	Solid tumor	331 (5.6%)
	Myasthenia	36 (0.6%)
History of thyroid disease N (%)	Graves' disease	4,427 (75.5%)
	Other dysthyroidism	1,345 (22.9%)
	Thyroid Cancer	77 (1.3%)
	Thyroid exeresis	774 (13.2%)
	Radioiodine therapy	96 (1.6%)

Ophthalmic symptoms at index stay

Proptosis	4,769 (81.3%)
Diplopia	906 (15.5%)
Proptosis and / or diplopia	5,295 (90.3%)
Palpebral atrophy	149 (2.5%)
Strabismus	336 (5.7%)
Corneal damage	114 (1.9%)
Optical neuritis	134 (2.1%)
Other	231 (3.9%)
At least one symptom	5,863 (99.9%)

Results

Treatment patterns in patients with at least one year of follow-up

Incident population (Sensitive algorithm - UB)		With at least one year of follow-up
		Overall
Systemic treatment N (%)	Total	N = 4,422
	At least one systemic treatment	**2,092 (47.3%)**
	Perfusions of intra DRG drug (likely intravenous cortisoids)	2,083 (47.1%)
	Tocilizumab	214 (4.8%)
	Rituximab	69 (1.6%)
	Teprotumumab	27 (0.6%)
Orbital radiotherapy, N (%)		**233 (5.3%)**
Eye surgery N (%)	At least one eye surgery	**976 (22.1%)**
	Orbital decompression	579 (13.1%)
	Eyelid surgery	370 (8.4%)
	Strabismus surgery	326 (7.4%)

40.4% the 1st year of follow-up

4.8% still the 3rd year

Stable treatment use (between 9% and 10%) throughout years 1–3 of follow-up

(Overall = At index stay + during the follow-up period)

Conclusion

First nationwide estimates of TED epidemiology in France and a general overview of patients hospitalized for TED in France between 2019 and 2023

Incidence rate consistent with previously reported European data[1,2]

Patient characteristics consistent with the known TED profile: predominance of women, mean age 50–54 years, and frequent proptosis

Management primarily based on systemic therapies, particularly intravenous corticosteroids, during the active phase

Delayed use of rehabilitative procedures, with eyelid and strabismus surgeries predominating during the second and third years of follow-up

Real-world treatment patterns reflecting current clinical practice in France

1. *Perros P, Hegedüs L, Bartalena L, Marcocci C, Kahaly GJ, Baldeschi L, et al. Graves' orbitopathy as a rare disease in Europe: a European Group on Graves' Orbitopathy (EUGOGO) position statement. Orphanet J Rare Dis. déc 2017;12(1):72.*
2. *Boulakh L, Nygaard B, Bek T, Faber J, Heegaard S, Toft PB, et al. Nationwide Incidence of Thyroid Eye Disease and Cumulative Incidence of Strabismus and Surgical Interventions in Denmark. JAMA Ophthalmol. 1 juill 2022;140(7):667. doi:10.1001/jamaophthalmol.2022.1002*

Thank you for your attention

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Methods (Complement)

The two complementary identification algorithms to identify study population

Specific algorithm
(Lower bound)

Sensitive algorithm
(Upper bound)

Restricted diagnosis codes:

- Ophthalmic symptom: H06.2
- Dysthyroidism: E05.0

Broader diagnosis codes:

- Ophthalmic symptom: H06.2, H05, H53.2, H02.5, H49, H50, H16.0, H16.3, H46, H58.8, H06.3
- Dysthyroidism: E05, E06.3

Algorithm:

- One hospitalization with the/at least one ICD-10 code of ophthalmic symptom (MCO, DP/DR) **AND** at least one ICD-10 code of dysthyroidism (MCO, DAS) within the same stay

OR

- One hospitalization with the/at least one ICD-10 code of dysthyroidism (MCO, DP/DR) **AND** the/at least one ICD-10 code of ophthalmic symptom (MCO, DAS) within the same stay

OR

- One hospitalization (MCO) with an administration of teprotumumab **AND** the/at least one ICD-10 code (MCO, DP/DR/DAS) of dysthyroidism **OR** the/at least one ICD-10 code (MCO, DP/DR/DAS) of ophthalmic symptom within the same stay

(ICD-10: International classification of disease tenth revision; DP: Main diagnosis; DR: Related diagnosis; DAS: Significant Associated Diagnosis)