Epidemiology and Treatment Patterns of Neuroendocrine Tumors in Germany: Insights from a National Cancer Registry

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KEY LEARNINGS

NETs show marked heterogeneity in epidemiology and treatment patterns, underscoring the need for subtype-specific real-world evidence to inform clinical decision-making.

BACKGROUND

- Neuroendocrine neoplasms (NENs) are rare, heterogeneous malignancies arising from neuroendocrine cells and include well-differentiated neuroendocrine tumors (NETs) and poorly differentiated neuroendocrine carcinomas (NECs).[1, 2]
- NETs can be classified by primary tumor site and grade (G1-G3) with differences in tumor biology, hormonal activity, and molecular profile shaping disease course and prognosis.[1, 2]
- This heterogeneity is mirrored in diverse treatment options, including active surveillance, surgery, somatostatin analogs (SSA), peptide receptor radionuclide therapy (PRRT), and systemic therapies such as targeted treatments, systemic chemotherapy, and emerging immunotherapeutic approaches.[3, 4]
- Given the expanding treatment landscape and increasing complexity of clinical decision-making, real-world evidence is needed to better characterize patients, treatment patterns, and outcomes across relevant subgroups.

OBJECTIVES

- To describe the epidemiology of NENs and characterize clinical heterogeneity of NETs in Germany, focusing on tumor localization, demographic and disease-related characteristics as well as treatment patterns of incident NET patients.

CONCLUSIONS

- The rapidly evolving treatment landscape for NETs increases the complexity of clinical decision-making and highlights the importance of timely subtype-specific guideline updates that incorporate new evidence.
- The registry-based analysis revealed substantial heterogeneity in tumor biology and treatment patterns across NET subgroups, highlighting the importance of real-world evidence in complementing clinical trial data.

METHODS

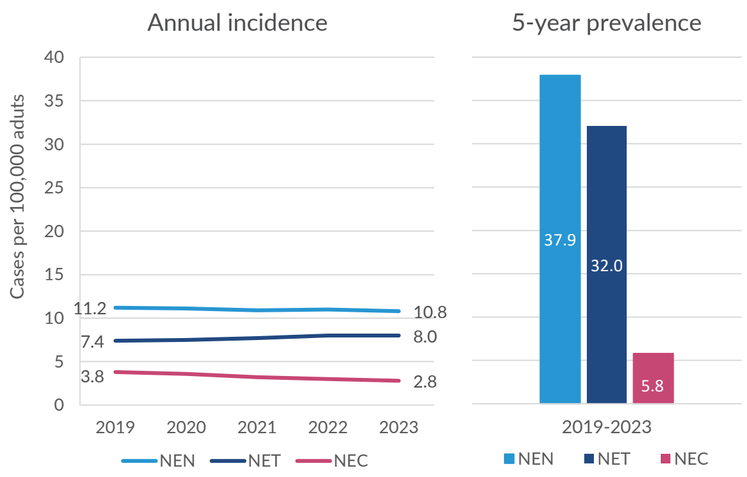
- A retrospective cohort study was conducted using the epidemiological and clinical dataset from the German Center for Cancer Registry Data (ZfKD). The former was utilized for the epidemiological analyses (2019-2023),[5] while the clinical dataset was used for the analysis of patient characteristics and treatment patterns of NET patients (2020-2023).[6]
- Adult patients with incident NET were identified based on ICD-10-GM and ICD-O-3 codes and stratified by tumor localization into pancreatic NET (PanNET), gastrointestinal NET (GI-NET), NET of the lung (LungNET), and Other NETs.
- Incidence and prevalence rates were calculated per 100,000 inhabitants (German adult population). Incidence reflects newly diagnosed patients, while prevalence reflects patients alive at the end of the observation period (5-year point prevalence).
- Radiation therapies were analyzed by pre-defined categories available in the registry, while surgeries were assessed by German procedure classification (OPS) codes and systemic treatment was identified and categorized via Anatomical Therapeutic Chemical (ATC) codes.

RESULTS

Incidence and prevalence of NEN, NET and NEC

- Annual incidence rates of NEN remained stable between 2019 and 2023, slightly decreasing from 11.2 to 10.8 per 100,000 adults. During this period, NET incidence increased from 7.4 to 8.0 per 100,000, while NEC incidence declined from 3.8 to 2.8 per 100,000 adults (**Figure 1**).

Figure 1. Annual incidence and 5-year prevalence rates



Treatment patterns of NET

- For the analysis of treatment patterns, 21,168 incident NET patients were included from the clinical dataset (2020-2023). Patients were stratified into 2,414 PanNET (11.4%), 13,152 GI-NET (62.1%), 4,192 LungNET (19.8%), and 1,500 Other NETs (7.1%) patients.
- Sex distribution varied across NET subgroups, with women comprising the majority of patients in LungNET and Other NETs, whereas men were slightly more prevalent in the PanNET and GI-NET cohorts (55.5% and 51.2%) (**Table 1**).

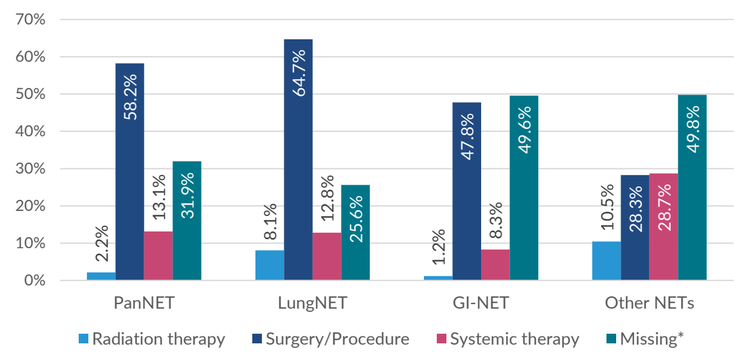
Table 1. Characteristics of NET patients

	PanNET (n=2,414)		LungNET (n=4,192)		GI-NET (n=13,152)		Other NETs (n=1,500)	
	n	%	n	%	n	%	n	%
Sex								
Female	1,074	44.5	2,711	64.7	6,420	48.8	825	55.0
Male	1,340	55.5	1,481	35.3	6,729	51.2	675	45.0
Unknown	0	0.0	0	0.0	3	0.0	0	0.0
Age at diagnosis								
18-29	46	1.9	65	1.6	532	4.0	14	0.9
30-39	81	3.4	140	3.3	718	5.5	48	3.2
40-49	165	6.8	288	6.9	1,179	9.0	93	6.2
50-59	508	21.0	737	17.6	2,963	22.5	203	13.5
60-69	677	28.0	1,253	29.9	3,360	25.5	394	26.3
70-79	638	26.4	1,186	28.3	2,727	20.7	420	28.0
≥80	299	12.4	525	12.5	1,680	12.8	328	21.9
Tumor grading*								
1	1,690	69.8	2,033	48.1	8,755	65.8	407	27.1
2	315	13.0	730	17.3	2,252	16.9	531	35.3
3	79	3.3	223	5.3	556	4.2	195	13.0
Other	45	1.9	218	5.2	385	2.9	83	5.5
Unknown	291	12.0	1,020	24.1	1,357	10.2	287	19.1

* As some patients in the dataset have more than one tumor, these numbers do not sum up to the number of patients.

- Surgery was the most frequent treatment across NET subgroups particularly in LungNET and PanNET. Radiation therapy was most common in Other NETs and LungNET, while systemic therapy was less frequent overall but most prominent in Other NETs (**Figure 2**).

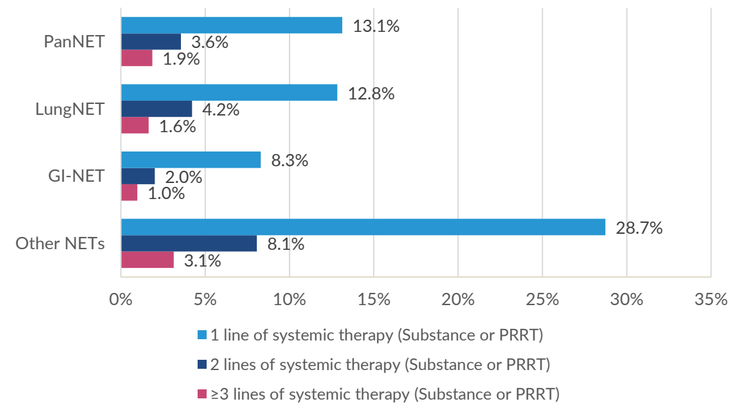
Figure 2. Overview of treatment options



* A distinction between patients who are on watch and wait and patients without valid information on any of the treatment options is not possible in the data.

- Among patients receiving systemic therapy, most patients received 1 line of systemic therapy, with proportions decreasing steadily across subsequent therapy lines in all subgroups (**Figure 3**).

Figure 3. Lines of systemic therapy



- In LungNET, platinum-based chemotherapy was the leading first-line regimen, most commonly etoposide plus carboplatin, indicating distinct treatment patterns compared with other NET subgroups (**Table 2**).

Table 2. Top 3 systemic first-line therapies

1L therapy regimen (substances)	n	% of treated
PanNET (n=2,414)		
Lanreotide	74	22.1
Octreotide	24	7.2
Streptozocin+Fluorouracil	20	6.0
LungNET (n=4,192)		
Etoposide+Carboplatin	117	21.5
Everolimus	50	8.8
Etoposide+Atezolizumab+Carboplatin	40	7.4
GI-NET (n=13,152)		
Lanreotide	314	27.9
Octreotide	130	11.7
Fluorouracil+Oxaliplatin	48	4.3
Other NETs (n=1,500)		
Lanreotide	79	18.3
Etoposide+Carboplatin	43	10.0
Octreotide	39	9.0

Abbreviations ATC: Anatomical Therapeutic Chemical; GI: gastrointestinal; ICD: International Classification of Diseases; Lung: pulmonary; NEC: neuroendocrine carcinoma; NEN: neuroendocrine neoplasm; NET: neuroendocrine tumor; OPS: German procedure classification; Pan: pancreatic; ZfKD: Center for Cancer Registry Data; SSA: Somatostatin analogs, PRRT: Peptide receptor radionuclide therapy.

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Presented at the ISPOR Annual European Congress | 08–11 Nov 2026.

Author contributions All authors provided substantial contributions to study conception/design, or acquisition/analysis/interpretation of data; drafting of the publication, or reviewing it critically for important intellectual content, and gave their final approval of the publication.

Disclosures SK received fees for speaking engagements from Novartis Pharma, Ipsen Pharma, Bristol Myers Squibb, AstraZeneca, LEO Pharma, SERB Pharmaceuticals, and Pierre Fabre. SG and HU are employees of Ipsen and may hold stock. KSK is an employee of Cencora, which received consulting fees from Ipsen.

Medical writing support The authors thank Kim-Sarah Krinke, Christopher Maas and Christian Jacob of Cencora, Hanover, Germany for providing medical writing and editorial support, which was sponsored by Ipsen in accordance with Good Publication Practice guidelines (GPP 2022).

This study was sponsored by Ipsen.