

A Cancer Registry Analysis of Neuroendocrine Neoplasms in Germany

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KEY LEARNINGS

Epidemiology of neuroendocrine neoplasms (NENs) in Germany.

BACKGROUND

- NENs represent a heterogeneous group of malignancies with increasing clinical relevance and socioeconomic impact.
- Due to a lack of precise epidemiological data, it is difficult to predict which clinical resources are necessary to provide comprehensive care for NENs.
- With the approval of new therapeutic options, LungNETs are also gaining more attention from healthcare professionals alongside GEP–NENs.
- Thus, reliable epidemiological data are essential for understanding disease burden and guiding healthcare planning.
- This retrospective analysis provides insights into incidence, prevalence, patient demographic, and tumor characteristics of NENs in Germany.

OBJECTIVES

To describe the incidence, prevalence, patient demographic and tumor characteristics of NENs in Germany using national cancer registry data.

CONCLUSIONS

- While the overall incidence of NEN remained relatively stable between 2019 and 2023, a divergent trend was observed between NEC and NET subtypes, with NEC incidence declining and NET incidence slightly increasing.
- Subgroup–specific data highlight the predominance of gastrointestinal NETs.
- In light of the relevant incidence and prevalence rates reported here, there is a clear need to increase awareness of LungNETs.
- These findings underscore the importance of standardized registry data.
- Further research is warranted to explore diagnostic trends, treatment patterns, and potential impacts of external factors.

METHODS

Retrospective analysis

- This retrospective analysis used data from German cancer registries¹ from 2019 to 2023.
- NEN cases were identified via ICD–O and ICD–10 codes, with subgroups defined as pancreatic NEN (panNEN), gastrointestinal NEN (GINEN), pulmonary NEN (LungNET), and other that included localization not distributed to gastroenteropancreatic (GEP)– or LungNET.

RESULTS

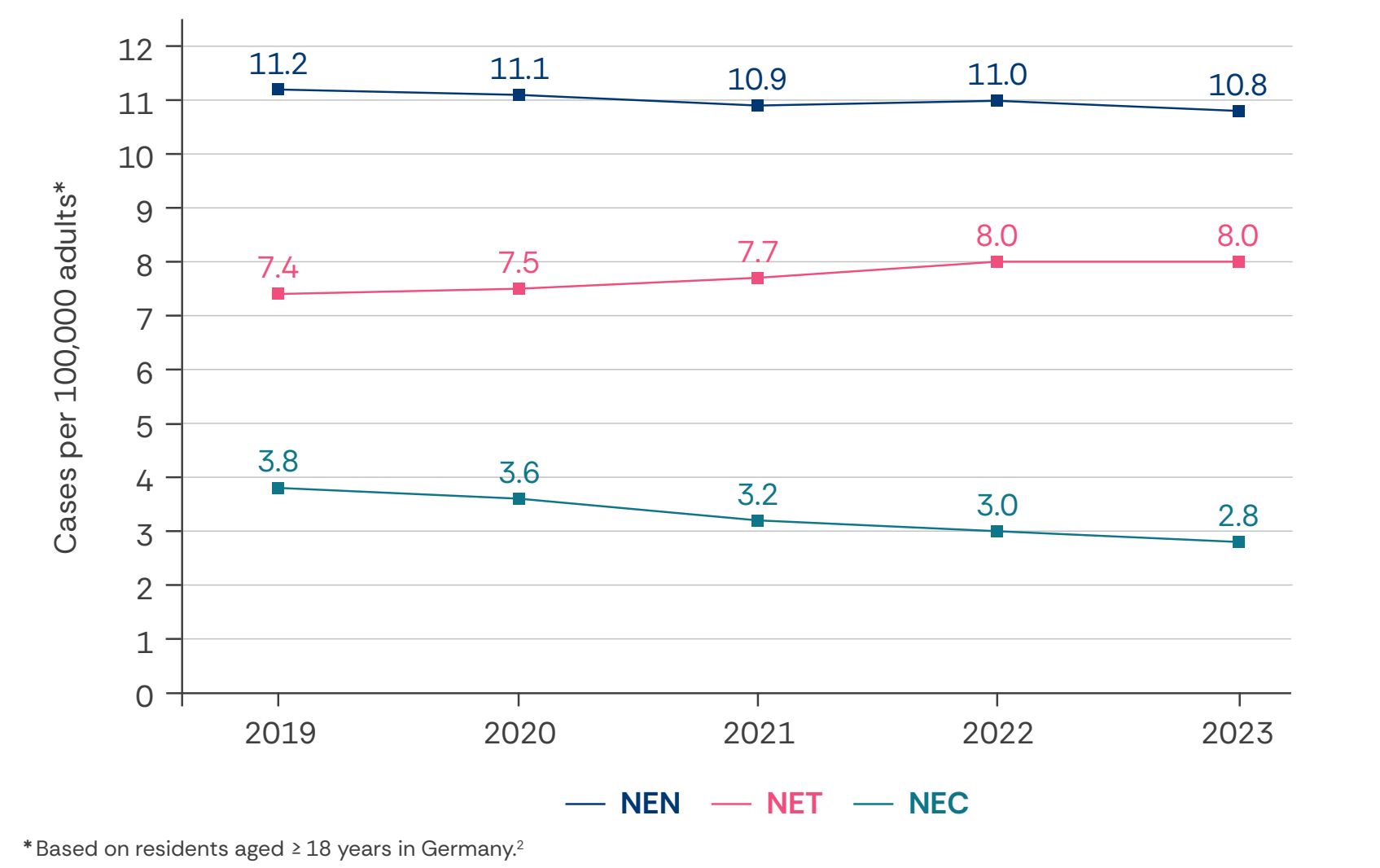
- In 2023, 7,497 incident NEN cases were recorded (NET: 5,567; NEC: 1,930), corresponding to an annual incidence rate of 10.8 per 100,000 adults.¹
- When stratified by neuroendocrine tumors (NETs) and neuroendocrine carcinomas (NECs), incidence rates were 8.0 and 2.8 per 100,000 adults, respectively.¹
 - Subgroup–specific incidence rates and the corresponding incident cases were recorded for panNET (0.9; 640); GINET (4.8; 3,348); LungNET (1.7; 1,205) and Other (0.6; 374).¹

Characteristics

- In 2023, the mean age at diagnosis of NEN was 65.1 years (SD = 14.2), of NEC was 69.3 years (SD = 12.3), and of NET was 63.6 years (SD = 14.5).¹
- Additionally, 51% of patients with NEN were male, 59% with NEC, and 48% with NET.¹

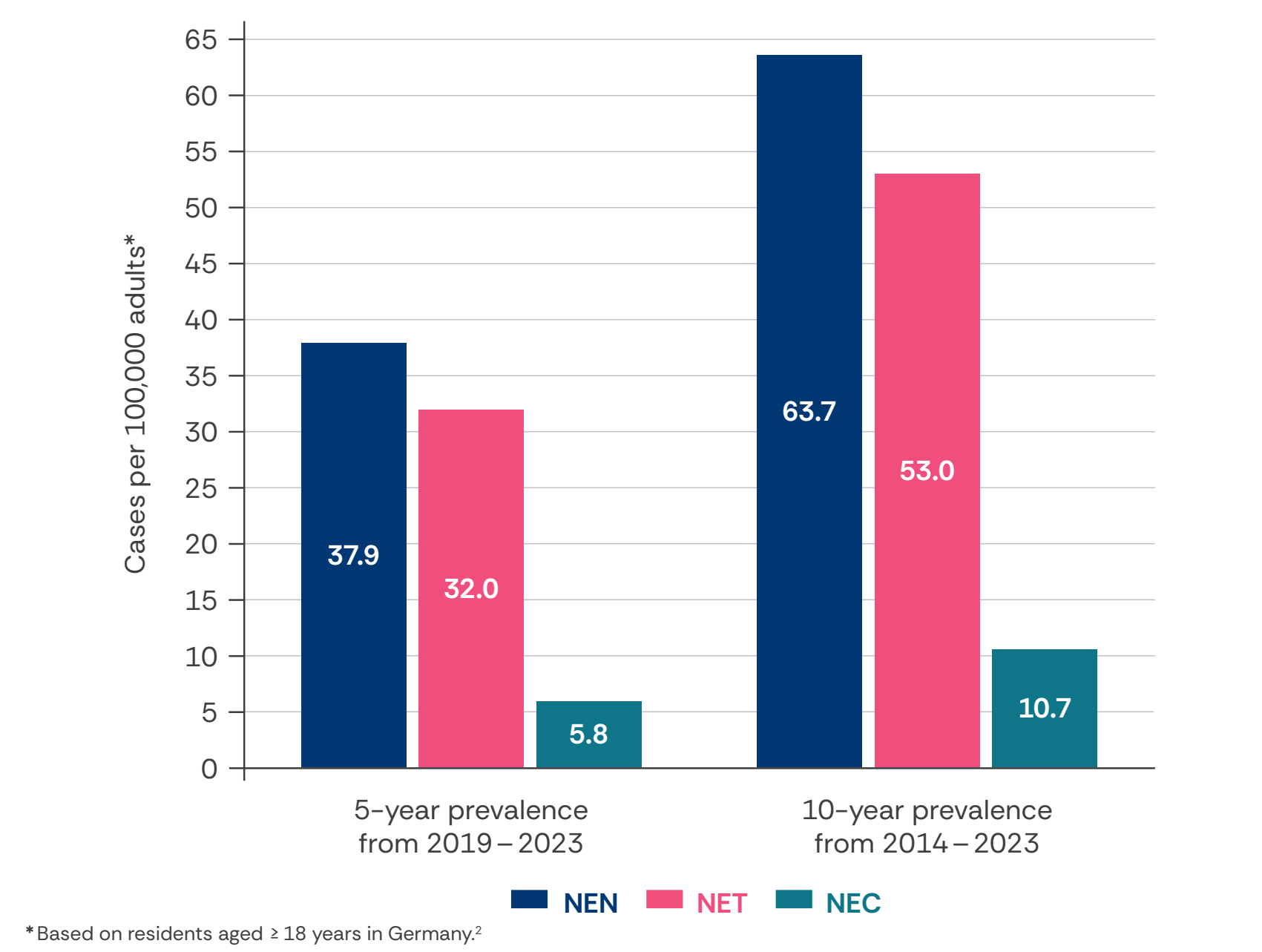
Incidence rates

Figure 1. Annual incidence rates¹



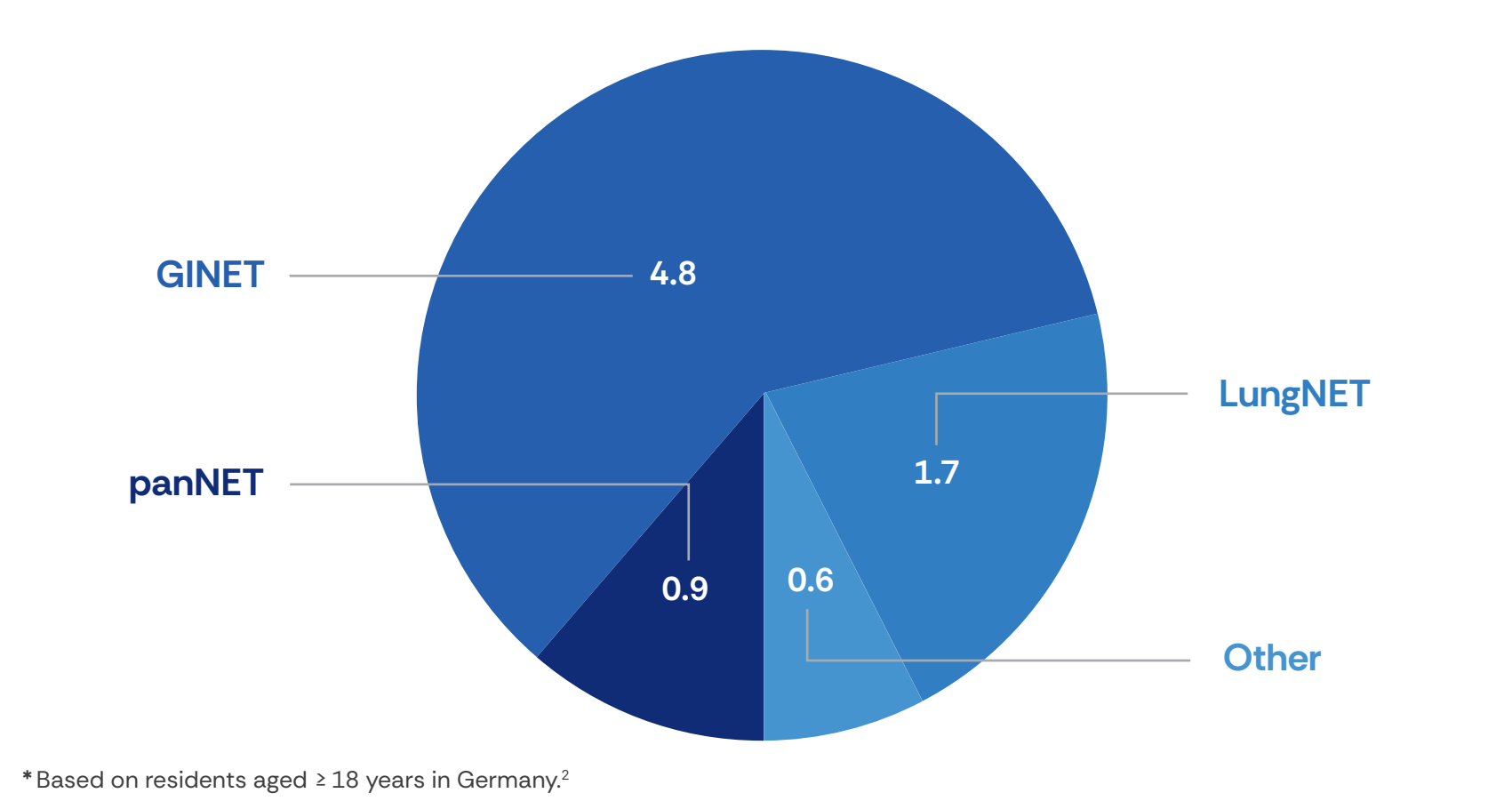
Prevalence rates

Figure 2. 5– and 10–year prevalence rates¹



Subgroup–specific rates of NETs

Figure 3. Subgroup–specific incidence rates of NETs from 2023 per 100,000 adults*¹



The three most frequent ICD codes within the “Other” category were: malignant neoplasm, unspecified; malignant neoplasm of the breast, and malignant neoplasm of the ovary.

Figure 4. Distribution of NET cases by age (2023)*¹

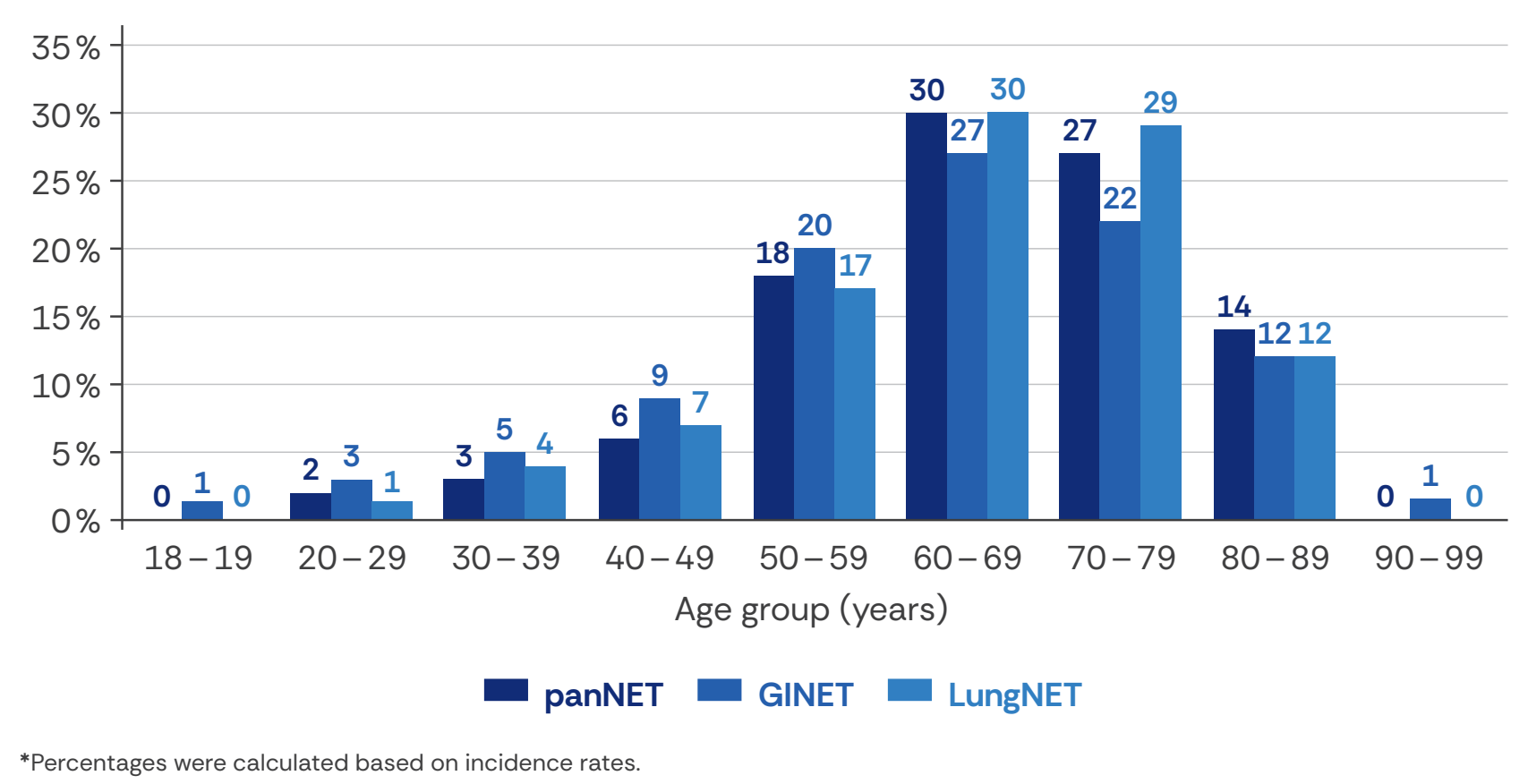


Table 1. Grading of NETs (2019–2023)*¹

	2019	2020	2021	2022	2023
Data are presented as panNET / GINET / LungNET.					
Grading, %					
1; Well differentiated	76/69/50	75/68/50	71/68/51	71/67/48	70/68/52
2; Moderately differentiated	10/18/20	12/18/18	14/18/17	14/17/20	14/17/18
3; Poorly differentiated	3/2/3	3/4/5	4/4/6	4/5/7	3/5/4
4; Undifferentiated	0/0/1	0/0/1	0/0/0	0/0/0	0/0/1
Missing grading information	9/9/26	9/9/26	10/8/26	12/9/24	13/9/24

*Percentages were calculated based on incidence rates.

LungNET¹

- In 2023, 1,205 incident LungNET cases were recorded.
- The mean age at diagnosis was 64.6 years (SD = 13.1).
 - The proportion of males was 34 %.

Table 2. Tumor location of LungNETs (2019–2023)*¹

	2019	2020	2021	2022	2023
Tumor location, %					
1 = left	37	38	40	41	38
2 = right	54	55	53	54	55
3 = bilateral	1	2	1	1	1
4 = not applicable	0	0	0	0	0
5 = central	0	0	0	0	0
Missing tumor location information	8	6	7	4	7

*Percentages were calculated based on incidence rates.

Abbreviations
GEP: gastroenteropancreatic; GEP–NEN: gastroenteropancreatic NEN; GI: gastrointestinal; ICD: International Classification of Diseases; Lung: pulmonary; LungNET: neuroendocrine tumor of the lung; NEC: neuroendocrine carcinoma; NEN: neuroendocrine neoplasm; NET: neuroendocrine tumor; pan: pancreatic; SD: standard deviation.

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2. Statistisches Bundesamt: Bevölkerungsstand; Available: <https://www.destatis.de/DE/Themen/Gesellschaft–Umwelt/Bevoelkerung/Bevoelkerungsstand/Tabellen/liste–altersgruppen–basis–2022.html#1343584>.

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
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