Real-World Management of Extrapulmonary Neuroendocrine Carcinoma (epNEC) from the Perspective of Healthcare Providers in the VOICE Study

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Introduction

- epNEC is a rare, aggressive malignancy arising outside the lungs, most commonly in the gastrointestinal and genitourinary tracts[1]

epNEC Diagnosis

Diagnosis is challenging and delays stem from the rarity of the disease, clinical and histopathologic overlap with well-differentiated NETs, and reliance on imaging-guided biopsy with immunohistochemical confirmation of neuroendocrine markers[2]

epNEC Treatment

HCPs may also face difficulties due to the heterogeneous pathological aspects as well as the therapeutic strategies. Current treatment for epNEC is primarily adapted from SCLC, with platinum-etoposide as the standard 1L regimen; however, no consensus exists for later-line treatment, resulting in substantial variability in clinical practice[3–6]

- However, real-world evidence describing HCP diagnostic and treatment practices for patients with epNEC remains limited

1L, first line; epNEC, extrapulmonary neuroendocrine carcinoma; HCP, healthcare provider; NET, neuroendocrine tumor; SCLC, small cell lung cancer

Objective

- This study aims to characterize the real-world patient journey, experiences, and unmet needs across the epNEC care pathway from the perspective of US HCPs

US, United States

Methods

- A cross-sectional, web-based survey of US HCPs was administered in January and February 2026
  - HCPs were recruited by a survey vendor using an HCP directory and referrals from the clinical experts'professional networks
  - Eligible HCPs were licensed US oncologists who had treated ≥1 patient with epNEC in the past 12 months at the time of the survey
- HCPs were stratified by practice setting (academic vs community)
- The study was deemed exempt from IRB review by Pearl IRB, under 45 CFR 46.104(d)(2)

CFR, code of federal regulations; IRB, Institutional Review Board

The survey included questions related to:

- ✓ Patient referral and diagnosis
- ✓ Utilization and adherence to diagnostic and treatment guidelines
- ✓ Treatment selection and satisfaction
- ✓ Biomarker testing
- ✓ Unmet needs

Key Findings and Conclusions

- The management of epNEC remains challenging, with HCPs reporting referral delays, diagnostic uncertainty, limited access to specialized pathology review, and limited satisfaction with currently available therapies
- Findings highlight HCPs' willingness to adopt biomarker-driven treatment, particularly DLL3-targeted strategies, and the opportunity to leverage these approaches to improve treatment selection and address unmet needs in epNEC

DLL3, delta-like ligand 3

Limitations

- The current study primarily included HCPs accessible through the survey panel vendor who wished to participate in this study. As a result, the sample may not be representative of US HCPs treating patients with epNEC. Selection bias may exist in the resulting sample of respondents due to the use of convenience sampling
- This study relied on HCPs' self-reported data, making the findings susceptible to recall bias

Respondent Characteristics

- A total of 100 HCPs participated in the study (**Table 1**)
  - Median age was 45 years, 77% were male, 82% were medical oncologists or hematologists/oncologists, 61% practiced in community settings, and 76% practiced in urban settings
  - HCPs were geographically representative of the US
  - HCPs had substantial experience managing epNEC
  - HCP characteristics were similar in the academic and community practice settings

Table 1. Patient characteristics

Characteristic	Overall (N=100)
Age (years), median [IQR]	45.0 [41.0–54.0]
Gender, n (%)	
Male	77 (77.0)
Female	21 (21.0)
Other/non-binary	1 (1.0)
Prefer not to answer	1 (1.0)
Medical subspecialty, n (%)†	
Medical oncologist and hematologist/oncologist	82 (82.0)
General oncologist	19 (19.0)
Gastrointestinal oncologist	16 (16.0)
Thoracic oncologist	16 (16.0)
Genitourinary oncologist	11 (11.0)
Breast oncologist	10 (10.0)
Head and neck oncologist	6 (6.0)
Gynecologic oncologist	5 (5.0)
Region of primary practice, n (%)	
South	36 (36.0)
West	25 (25.0)
Midwest	20 (20.0)
Northeast	19 (19.0)
Practice setting, n (%)	
Community hospital	61 (61.0)
Academic/teaching hospital	38 (38.0)
Other	1 (1.0)
Area of primary practice, n (%)†	
Urban	76 (76.0)
Suburban	22 (22.0)
Rural	6 (6.0)
Health insurance accepted, n (%)†	
Commercial insurance	97 (97.0)
Medicare	96 (96.0)
Medicaid	92 (92.0)
Other (e.g., VA, TRICARE, or other public coverage)	40 (40.0)
Years practicing as an oncologist after residency/fellowship	
Median [IQR]	16.0 [11.0–20.0]
Years actively treating adult patients with epNEC	
Median [IQR]	11.0 [6.0–16.5]
Patients with poorly differentiated epNEC treated in the past 12 months	
Median [IQR]	13.0 [4.0–40.0]

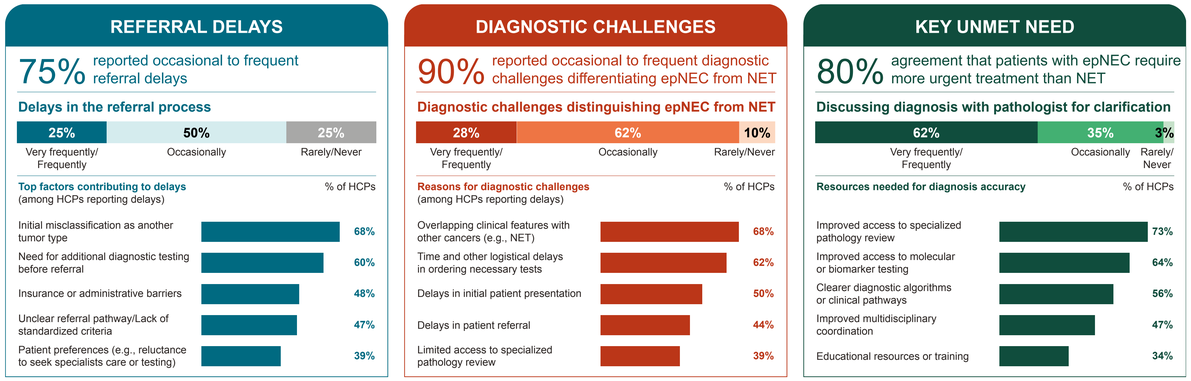
†Categories are not mutually exclusive
IQR, interquartile range; VA, Veterans Affairs

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Diagnostic Challenges

Figure 1. Referral delays and diagnostic challenges



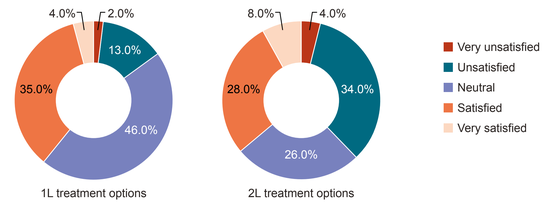
Nearly one-third (31%) of HCPs reported ≥1 month from initial patient contact to referral to oncologists

Treatment Selection and Satisfaction

- Clinical guidelines, particularly NCCN, were most influential in diagnostic and treatment decision-making
  - 92% of HCPs always or often relied on guidelines for treatment vs 75% for diagnosis; 96% of HCPs reported being fully or mostly aligned with guidelines for treatment vs 82% for diagnosis
  - For making diagnostic decisions, 89% of academic HCPs vs 66% of community HCPs always or often consulted guidelines
- ~80% of HCPs agreed that epNEC requires more urgent treatment than NET
  - In 1L, platinum-etoposide–based regimens were the most common (59%), followed by immunotherapy-based regimens (25%)
  - Platinum-etoposide use was higher in academic settings (68% vs 53%); immunotherapy use was higher in community settings (30% vs 18%)
  - 2L treatment selection was heterogeneous, reflecting the absence of a clear standard of care
- Nearly two-thirds of HCPs reported neutrality or dissatisfaction with available 1L (61%) and 2L (64%) treatment, with efficacy identified as the greatest unmet need (**Figure 2**)

Primary treatment goals:
1L: prolong survival
2L: relieve symptoms and improve QoL

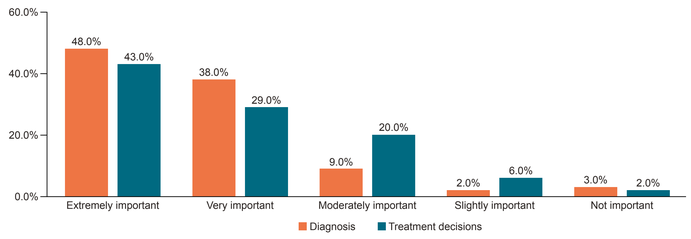
Figure 2. Satisfaction with currently available 1L and 2L treatment options



2L, second line; NCCN, National Comprehensive Cancer Network; QoL, quality of life

Biomarker Testing

Figure 3. Importance of biomarker testing in informing diagnosis and treatment decisions



- Biomarker testing was widely considered important for both diagnosis (95%) and treatment decisions (92%) (**Figure 3**)
- ~83% of HCPs reported familiarity with DLL3 as a potential therapeutic target for epNEC
- ~68% of HCPs reported testing for DLL3 during patients' epNEC treatment journey. Among these:
  - 75% used immunohistochemistry
  - 49% used next-generation sequencing
- Among HCPs not currently testing for DLL3, 78% would be willing to order DLL3 testing to inform treatment selection

Overall, 91% of HCPs would consider DLL3-targeted therapy for eligible patients

Patient Support Needs

HCPs identified improved reimbursement and financial navigation (69%) and clinical education regarding treatment expectations and side effects (64%) as the patient care support services most in need of improvement

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