Real-World Patient Journey in Extrapulmonary Neuroendocrine Carcinoma (epNEC): Perspectives of Patients from the VOICE Study

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Introduction

- epNEC is a rare, aggressive malignancy with poor prognosis and limited treatment options[1]
- The diagnostic process is complex with potential delays stemming from the disease's rarity, symptom overlap with other conditions, and the need for biopsy and multiple specialist referrals[2,3]
- As a result, patients often undergo extensive diagnostic workups but the evidence characterizing the patient journey is limited
- This study represents one of the largest efforts to date, aiming to comprehensively characterize the epNEC patient journey and unmet needs from the patient perspective

epNEC, extrapulmonary neuroendocrine carcinoma

Objective

- This study aims to characterize the patient journey and identify unmet needs of US adults with epNEC, including symptoms, diagnosis, treatment, and health-related QoL, from the patient perspective

QoL, quality of life, US, United States

Methods

- A cross-sectional online survey of US adults with epNEC was conducted from November 2025 to February 2026

Inclusion criteria

- Eligible patients were aged ≥18 years, resided in the US, and reported a diagnosis of epNEC or MiNEN/MANEC with a NEC component
- Patients were recruited through national patient advocacy organizations and online research panels

Assessments

- Data collection included patient characteristics, diagnosis, treatment history, biomarker testing, and unmet needs
- Health-related QoL was assessed using the PROMIS-GH-10 questionnaire
- Work productivity and activity impairment were assessed using the WPAI:SHP questionnaire

- This study was exempt by the Pearl IRB under 45 CFR 46.104(d)(2)

CFR, code of federal regulations; IRB, Institutional Review Board; MANEC, mixed adenocarcinoma neuroendocrine carcinoma; MiNEN, mixed neuroendocrine non-neuroendocrine neoplasm; NEC, neuroendocrine carcinoma; PROMIS-GH-10, Patient-Reported Outcomes Measurement Information System Global Health 10-item; WPAI:SHP, Work Productivity and Activity Impairment: Specific Health Problem

Study Population

- A total of 226 eligible patients participated in the study (**Table 1**)
  - Median age was 51 years, 67% were male, 59% were White, 56% were employed (35% full-time, 13% part-time, and 8% self-employed), and 50% had commercial insurance
  - Nearly 79% had GEP-NEC (64% gastrointestinal and 15% hepatopancreatobiliary), and 49% were diagnosed with Stage III/IV disease
- Most patients (96%) reported having a care partner, most commonly a spouse or partner (61%)

GEP-NEC, gastroenteropancreatic neuroendocrine carcinoma

Treatment Experience

- Across 1L and 2L, primary treatment goals for patients were consistently prolonging life, followed by improving QoL and minimizing side effects
- Treatment efficacy, side effects, and prognosis were critical factors commonly discussed for 1L and 2L treatment decision-making
- Chemotherapy dominated 1L (73%) while treatment was heterogeneous in 2L
- Although only 66% of patients underwent prior biomarker testing, 94% were willing to undergo testing to inform treatment selection
- Over 65% traveled ≥30 minutes 1-way to receive treatment; 23% reported delays in receiving care due to transportation issues

1L, first line; 2L, second line

Patient Support

- Oncologists were the primary source of information for epNEC management (95%)
- The highest unmet needs were access to specialists with new/novel therapies, greater involvement in decision-making, and useful educational resources to better understand epNEC

Key Findings and Conclusions

- Patients with epNEC experience a prolonged and complex diagnostic journey, driven by nonspecific symptoms and delays in seeking care and obtaining a diagnosis, highlighting the need for improved awareness and earlier referral pathways
- The substantial burden of epNEC on physical and mental health, work productivity, and daily activities underscores the need for better patient education and greater resources throughout the care journey
- Together with patients' strong engagement in their care, these findings highlight opportunities across the epNEC care continuum to support earlier diagnosis and specialist care, address broader patient needs, and facilitate shared decision-making and biomarker-informed treatment

Table 1. Patient characteristics

Characteristic	Overall (N=226)
Demographic characteristics	
Age (years), mean (median) ± SD	52.0 (50.5) ± 12.2
Gender, n (%)	
Male	151 (66.8)
Female	75 (33.2)
Race/ethnicity, n (%)†	
White or Caucasian	134 (59.3)
African American/Black	65 (28.8)
Hispanic or Latino	15 (6.6)
Asian or Pacific Islander	13 (5.8)
Native American or Alaskan Native	5 (2.2)
Employment status, n (%)	
Employed	126 (55.8)
Homemaker	22 (9.7)
Unemployed	18 (8.0)
On disability leave	8 (3.5)
Retired	52 (23.0)
Health insurance coverage, n (%)†	
Commercial insurance	112 (49.6)
Medicare	90 (39.8)
Medicaid	33 (14.6)
Other	4 (1.8)
Uninsured	5 (2.2)
Care partner support, n (%)‡	
Yes, always	99 (43.8)
Yes, most of the time	91 (40.3)
Yes, sometimes	27 (11.9)
No	9 (4.0)
Relationship of care partner to patient, n (%)§	**N=217**
Spouse/partner	132 (60.8)
Child	42 (19.4)
Other family member	18 (8.3)
Parent	14 (6.5)
Friend/neighbor	5 (2.3)
Other	6 (2.8)
Clinical characteristics	
Primary location, n (%)	
Gastrointestinal (e.g., stomach, esophagus, colon, anus, rectum)	145 (64.2)
Hepatopancreatobiliary (e.g., pancreas, bile duct, gallbladder)	33 (14.6)
Genitourinary except prostate (e.g., kidney, ureter/urethra, bladder)	17 (7.5)
Gynecologic (e.g., breast, cervix, uterus)	16 (7.1)
Head/neck (e.g., thymus, larynx)	12 (5.3)
Unknown	3 (1.3)
Stage of epNEC at diagnosis, n (%)	
Stage I/II	112 (49.6)
Stage III/IV	111 (49.1)
I don't know	3 (1.3)

†Categories are not mutually exclusive. ‡A care partner/caregiver was defined as a family member or friend who, without pay, helps a person because of his/her/their diagnosis of epNEC. §Asked among patients who reported having care partner support
SD, standard deviation

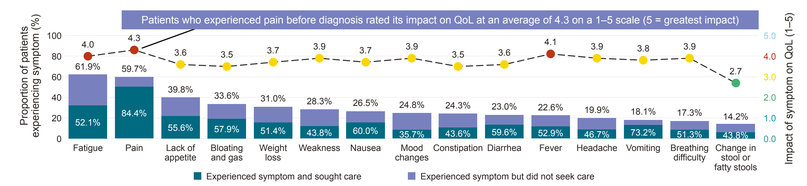
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1. Dasari A, et al. Cancer 2018;124:807–15; **2.** Stelwagen J, et al. JAMA Oncol 2021;7:759–70; **3.** Andreatos N, et al. Curr Oncol Rep 2023;25:1127–39

Symptoms and Diagnostic Journey

- Fatigue (62%) and pain (60%) were the most common symptoms experienced by patients prior to diagnosis (**Figure 1**); among patients who experienced these symptoms, pain (84%) and fatigue (52%) most often prompted patients to seek medical care
  - Other symptoms included confusion, insomnia, urinary problems, dysphagia, edema, reflux/heartburn, facial flushing, jaundice, enlarged lymph node, sexual dysfunction, and seizures
  - Symptoms reported to have the greatest impact on QoL included pain, insomnia, urinary problems, and sexual dysfunction
- More than half of patients (54%) waited more than 1 month between symptom onset to their first provider visit; mainly due to personal issues (e.g., time burden and lack of awareness; 62%) and waiting for symptoms to resolve (58%)
- Around 12% of patients took more than 3 months between initial provider contact to diagnosis confirmation; the most common reasons were inconclusive test results (46%) and referrals to multiple specialists (39%)
- Prior to diagnosis, 14% of patients visited an urgent care center and 12% visited an emergency room. The most consulted healthcare providers were primary care providers (76%) and gastroenterologists (37%)

Figure 1. epNEC-related symptoms experienced before diagnosis and its impact on QoL

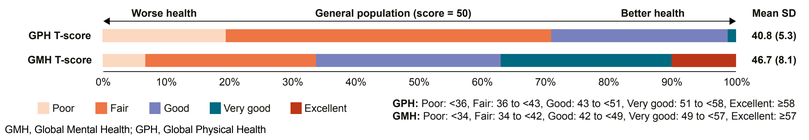


Note: The proportion of patients who experienced each symptom (reported in black text) was calculated among all patients (N=226), while the proportion of patients who sought care for each symptom (reported in white text) was calculated only among patients who experienced this symptom. Only the 15 most commonly experienced symptoms are shown

Impact of epNEC on QoL, Functioning, and Work

- The most impactful aspects of receiving a diagnosis were relief from identifying the symptom cause (mean score 1.9; 1 = most impactful to 5 = least impactful), emotional distress (2.3), and positive lifestyle changes (2.4)
- Disease burden was substantial, with mean PROMIS-GH-10 Global Physical and Mental Health T-scores of 40.8 and 46.7, both below the general-population norm (mean 50; lower T-scores indicating poorer health) (**Figure 2**)

Figure 2. Distribution of PROMIS GPH and GMH T-scores

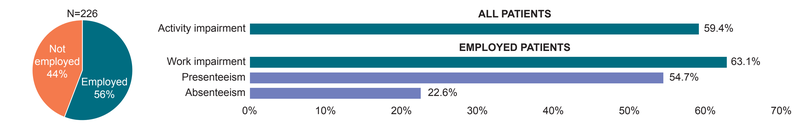


GPH: Poor: <36, Fair: 36 to <43, Good: 43 to <51, Very good: 51 to <58, Excellent: ≥58
GMH: Poor: <34, Fair: 34 to <42, Good: 42 to <49, Very good: 49 to <57, Excellent: ≥57

GMH, Global Mental Health; GPH, Global Physical Health

- Based on the WPAI, epNEC was associated with, on average, a 60% impairment in patients' ability to perform regular daily activities (**Figure 3**)
- Among employed patients (56% of the sample), overall work impairment was 63%, with absenteeism (work time missed) at 23% and presenteeism (impairment while working) at 55%

Figure 3. Work productivity and activity impairment specific health problem: impairment percentages



Note: Work impairment reflects productivity loss due to both presenteeism (reduced productivity while working) and absenteeism (work time missed)

Limitations

- Findings may not be fully generalizable to the broader epNEC population, as patients with more advanced illness may have been less likely to participate, and online recruitment may preferentially include younger, healthier, or more digitally engaged individuals
- Only patients with a confirmed diagnosis of epNEC were included. As a result, this limitation may lead to an underestimation of the barriers encountered by patients during the diagnostic journey
- This study relied on patients' self-reported data, making the findings susceptible to recall bias

This study was funded by Boehringer Ingelheim. The authors meet criteria for authorship as recommended by the International Committee of Medical Journal Editors (ICMJE). The authors did not receive payment related to the development of the poster. The authors were fully responsible for all content and editorial decisions, were involved at all stages of poster development, and have approved the final version. Boehringer Ingelheim was given the opportunity to review the poster for medical and scientific accuracy as well as intellectual property considerations. Medical writing support for the development of this poster, under the direction of the authors, was provided by Beatriz Albuixech Crespo, PhD, and Alba Bellot, PhD, employees of Boehringer Ingelheim, and funded by Boehringer Ingelheim

Aman Chauhan reports advisory roles with Novartis, Curium, Sanofi, Exelixis, Tersera, Ipsen, and Boehringer Ingelheim

Presented at the North American Neuroendocrine Tumor Society (NANETS) symposium, Las Vegas, NV, USA, November 5–7, 2026

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Previously presented at the European Society of Medical Oncology (ESMO) congress, Madrid, Spain, October 23–27, 2026

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