Neuroendocrine tumors (NETs) are rare, heterogeneous neoplasms whose incidence has increased 5-8x over the past 30 years due to greater population awareness and accurate diagnosis. Diagnosis of NETs often occurs late in the course of the disease:

- Symptoms of NETs may be nonspecific and may resemble other conditions such as intussusception (IBD) or adhesions. Some patients remain asymptomatic until metastasis occurs.

- NET-related symptoms persist a median of 6 months before NETs are diagnosed, at which point many patients have advanced disease.

- Up to 60% to 65% of gastrinomas are NETs at the time of diagnosis.

- Delayed diagnosis can substantially impact patient survival.

- NET diagnosis is an important prognostic factor with substantially better outcomes for locally advanced disease compared with distant metastases.

The initial NET experience was characterized by a long and challenging diagnosis, likely due to the rarity of these tumors. The presence of complications such as hormonal syndromes may persist a median of 9 years before NETs are diagnosed, at which point patients may have advanced disease and are at risk for complications.

The rareness of NETs, their heterogeneous nature, and the presence of symptoms with other, more common conditions can lead to delayed diagnosis. Early diagnosis and access to the latest treatments can improve outcomes for patients with NETs. The work presented in this study demonstrates the importance of timely diagnosis and the need for increased awareness and resources for patients with NETs.

The study involved a survey of 1,928 patients diagnosed with NETs from across the globe, who shared their experiences with diagnosis and treatment. The goal was to increase understanding of the NET patient experience and improve care for patients with NETs.

### Health care resource use

- Patients were asked if they had an HCP who helped them manage their NET, with a large majority (86%) reporting that they did.

- The types of HCPs patients interacted with included doctors, nurses, nutritionists, and dietitians.

- Patients identified several areas for improvement in the NET diagnostic process, including better access to information, more immediate access to NET expertise, and better support systems for patients.

### Conclusions

- Patients felt many aspects of NET diagnosis could be improved, including receiving clear information on long-term impact (85%), increased access to HCPs with NET expertise (55%), and more knowledgeable HCPS (46%).

- The survey results highlight the need for increased awareness and resources for patients with NETs, with patients reporting a desire for more information, better access to NET expertise, and improved support systems.

### References


