Patient-Reported Time to Diagnosis of Neuroendocrine Tumors (NETs) in Europe: Results From the First Global NET Patient Survey—
A Collaboration Between the International Neuroendocrine Cancer Alliance (INCA) and Novartis

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BACKGROUND

- Diagnosis of NETs often occurs late in the disease course.
- Symptoms are nonspecific, and some patients remain asymptomatic until an advanced stage.
- NET-related symptoms may persist for many years before NETs are diagnosed, by which point metastases have developed in most patients.
- Delayed diagnosis can substantially worsen prognosis.
- Localized disease is associated with substantially better outcomes than advanced disease with distant metastases.
- Although NET awareness and diagnostic techniques have improved, diagnosis remains challenging, and the NET patient experience has not been well examined.
- INCA is a network of 18 independent charitable organizations and patient groups from 15 countries around the world. Novartis Pharmaceuticals Corporation collaborated with INCA on the first global survey to gather data about the NET patient experience from multiple countries, with the goal of learning individual patient experiences of a NET diagnosis to increase understanding of the NET journey and the needs of patients with NETs.
- Highlighting differences and similarities between countries and regions to help improve NET awareness and care.
- We present European (EU) patient-reported data on time to diagnosis in NETs.

OBJECTIVE

- To raise awareness of the NET patient perspective, including challenges faced while seeking a diagnosis.

METHODS

- From February through May 2015, patients with NETs participated in a 25-minute anonymous survey that captured the NET patient experience, including their diagnosis.
- With the exception of certain demographic information, survey questions were closed-ended; participants were provided options from which to choose.
- Patients were recruited via use of flyers, social media platforms, e-mails, and social media channels of the INCA member organizations/patient advocacy groups (in 2014, INCA consisted of 17 organizations in 14 countries).
- Extensive use of online social media within local/regional advocacy groups allowed recruitment of a large number of patients with this rare type of cancer.
- Primarily conducted online and available in 8 languages: Bulgarian, Dutch, English, French, German, Norwegian, Spanish, and simplified Chinese.
- Paper surveys were developed in several languages and distributed by patient groups and health care providers (HCPs) to reach patients without internet.
- Data were analyzed at global, regional, and country levels; here we present results from the EU data.

RESULTS

DEMOGRAPHICS

- A total of 1025 patients with NETs were recruited from 12 countries in the Americas, Asia, Europe, and Oceania (Figure 1).
- The majority of respondents were from EU (n = 783) and North America (n = 222).

COUNTRIES: Participating in the global patient survey.

DIAGNOSTIC CHALLENGES

- For nearly half of the patients (53%), NET was not the initial diagnosis (Figure 6).
- About one-quarter of patients (28%) reported being diagnosed with NETs only after consulting with their physician. NET was not the initial diagnosis, consistent with findings in the literature, and social stress on the extensive use of health care resources associated with establishing a NET diagnosis.
- Improvements in time to diagnosis over the last 5 years suggest that awareness of NETs is increasing among physicians, but many patients continue to be diagnosed with other conditions, some more than once, before receiving a NET diagnosis. A considerable need exists to diagnose NETs earlier in the disease course, thereby improving patient survival.
- HCP communications regarding NETs at the time of diagnosis have an important influence on how patients feel about their disease.
- Patients identified several areas for improvement in the NET diagnostic process:
- They generally desired clearer, more detailed information on their disease and their NET's resources and knowledgeable HCPs.

REFERENCES

1. Pavel M, Goldston G, Lodden J, et al. Patient-Reported Time to Diagnosis of Neuroendocrine Tumors (NETs) in Europe: Results From the First Global NET Patient Survey—A Collaboration Between the International Neuroendocrine Cancer Alliance (INCA) and Novartis. Poster presented at: ECE 2015. Novartis Pharmaceuticals Corporation provided funding for the survey. © 2015 Novartis Pharmaceuticals Corporation, used under license by INCA and its member organizations.

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