

Neuroendocrine Tumor (NET) Patient Experiences Demonstrate Challenges of Diagnosing this Cancer

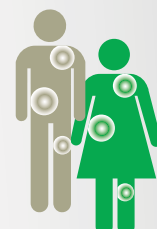
Results from the First Global NET Survey

A Collaboration between the International Neuroendocrine Cancer Alliance (INCA) and Novartis

About NET



Neuroendocrine tumors (NETs) are a type of cancer that can occur throughout the body. Some people with NETs may remain undiagnosed for years due to vague signs or symptoms, or even lack of symptoms. Even people who experience symptoms may not be diagnosed easily because NET symptoms can be similar to other diseases and conditions

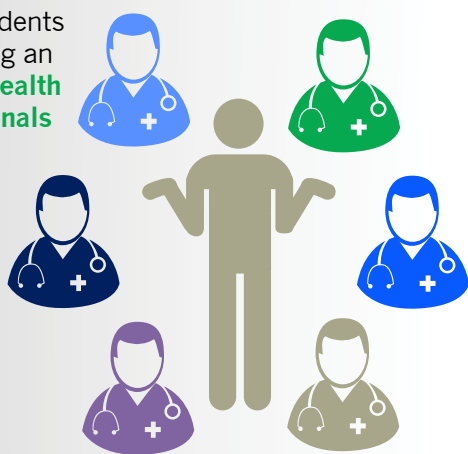


The stage of NET at diagnosis is important, as localized disease is associated with better patient outcomes. Many patients with NETs are diagnosed once the disease has spread to other parts of the body, making management more difficult

Survey Results:

Diagnosis Process

Survey respondents reported seeing an average of **6 health care professionals** (HCPs) prior to their NET diagnosis



25% of patients reported being diagnosed for NET as a result of being tested for something else

Only a **minority of respondents (18%)** were diagnosed at a NET specialist center



34% needed 7 or more doctor visits

48% Nearly half of respondents reported having 5 or more doctor visits until they received their diagnosis



45% Almost half of respondents reported not receiving NET as the first diagnosis. The most common initial diagnosis was for a digestive disorder, such as IBS (**39%**) or gastritis (**38%**). Some patients reported being diagnosed with a psychiatric disorder (**10%**) prior to receiving their NET diagnosis. Patients also reported being diagnosed with menopause (**12%**), asthma (**13%**) or anxiety/psychosomatic-type condition (**22%**).

Patients and Their NET Diagnosis

Respondents reported room for improvement in diagnostic experience

58% of respondents reported that their NET had metastasized, or spread to other parts of the body at time of their diagnosis

The survey showed that the median time from patient-reported symptom onset to a NET diagnosis was 24 months. However, **29%** of patients still required over 5 years for a NET diagnosis



Before they were diagnosed with a NET, **76%** of respondents did not think that their symptoms could be the result of a cancer

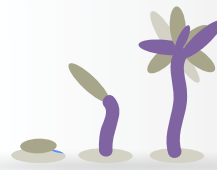
Upon diagnosis with NETs, patients typically felt shocked (**59%**), scared (**58%**), uncertain (**53%**), and bewildered (**40%**)



71% of respondents agree with the statement: "I think there is a lot of **room for improvement** in the process of diagnosing NET." This includes receiving clearer information on long-term impact (**60%**) and more immediate access to HCPs with NET expertise (**53%**)

- OUTSTANDING
- GOOD
- SATISFACTORY
- NEEDS IMPROVEMENT

At the time of diagnosis, many respondents had the impression from their doctors that NET was an "unusual type of cancer" that grows "**in slow motion**"



About the Survey

The goal of the Global NET Survey was to increase understanding of the experiences, needs and challenges of patients with NET, and provide insights and learnings among countries and regions to advance NET care.

From February through May 2014, **1,928 respondents** who reported that they were diagnosed with NET participated in a 25-minute online survey, available in 8 languages. Participants were recruited by INCA member organizations through flyers, website postings, e-mails, social media and other channels. The survey was a collaboration between INCA and Novartis, and funded by Novartis. Hall & Partners, a communications research agency, fielded and analyzed the results.

The Global NET Survey had several limitations that may have impacted results:

- A patient-reported design was employed without independent verification, leading to potential recall bias
- Life quality was evaluated using a multiple choice questionnaire and did not utilize standardized, validated quality-of-life assessments
- Recruitment was conducted primarily through patient advocacy groups (37%) and online sources (51%), which may have resulted in a potentially biased sample not fully representative of the heterogeneous NET patient population
- Respondents were more likely to be highly engaged and motivated care seekers, including female patients and/or those with a poorer prognosis

