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.

Survey respondents reported seeing an average of 6 health care professionals (HCPs) prior to their NET diagnosis. Only a minority of respondents (18%) were diagnosed at a NET specialist center.

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.

Survey 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%).

Respondents reported room for improvement in diagnostic experience. 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%).

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”.

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.

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