

Patients with Neuroendocrine Tumors (NETs) Report Impact on Life Quality

Results from the First Global NET Survey

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

About NETs

Neuroendocrine tumors (NETs) are rare tumors that can produce and secrete a variety of hormones that regulate bodily functions

5 OUT OF EVERY
100,000



PEOPLE ARE DIAGNOSED
WITH NETs EACH YEAR



60-80%

of patients are diagnosed at an advanced stage, often because symptoms can be similar to those associated with other conditions.

Life Quality



56% of patients experienced general fatigue, muscle fatigue and weakness due to their NET

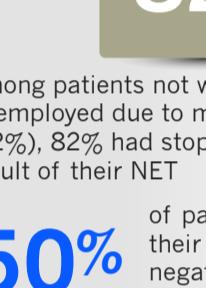


NETs have a moderate to significant negative impact on 71% of patients' lives

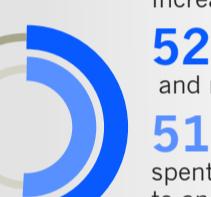


92% of patients made a lifestyle change as a result of their NETs

Work and Finances



Among those currently working (39%), 49% took days off work due to their NET



Among patients not working or unemployed due to medical disability (22%), 82% had stopped working as a result of their NET

50%

of patients reported their finances were negatively impacted by their NET

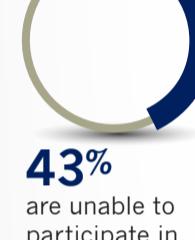


spent on travel to and from medical appointments

Emotional Health



Emotional health is negatively affected by having NETs



worry about uncertainty of the future



are unable to participate in activities they used to enjoy



deal with significant stress and anxiety levels



feel confused about the management of their disease

Lifestyle

Lifestyle is negatively affected by having NETs

54% ability to participate in leisure activities

70% overall energy levels

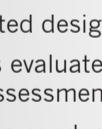
Patients with NETs made several lifestyle changes as a result of their disease, including:

58% Changes in diet

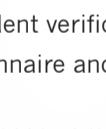
49% Stop or cut back on physical activity

43% Stop or cut back on social life

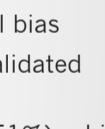
Overall, patients feel that...



a better understanding of how to manage disease-related symptoms (41%)



increased awareness of NETs (42%)



improved access to a NET medical team (43%)

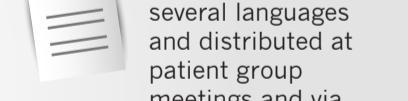
...would help them to live a better life

About the Survey

The goal of the 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 on a global level.

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



Methodology

The survey was fielded from

February - May 2014

1,928 patients from



12 countries took the survey



The survey was made available in eight languages, and participating INCA member organizations invited patients with NETs to participate in the 25-minute online anonymous survey via flyers, website postings, emails and social media channels



Paper surveys were developed in several languages and distributed at patient group meetings and via healthcare professionals to reach patients without access to the internet

Participant Patient Population

Patient Demographics:



Canada: n=164 (9%) United States: n=758 (39%) United Kingdom: n=156 (8%) France: n=117 (6%) Germany: n=311 (16%)

Other Europe: n=179 (9%) Japan: n=81 (4%) Oceania: n=138 (7%) Singapore and other Asia: n=18 (1%)

Other Americas (North, South, Central): n=6 (<1%)

Type of NET:

