

# 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**

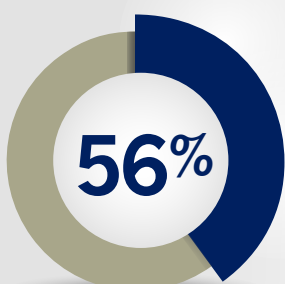
PEOPLE ARE DIAGNOSED WITH NETs EACH YEAR



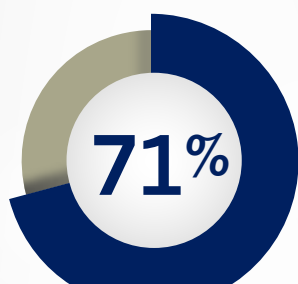
**60-80%**

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

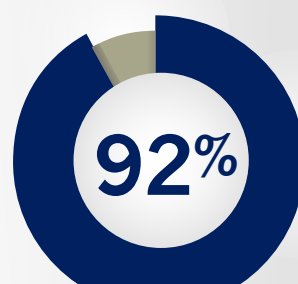
### Life Quality



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

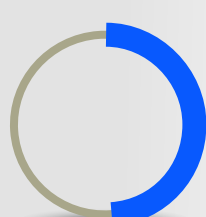


NETs have a moderate to significant negative impact on 71% of patients' lives



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

### Work and Finances



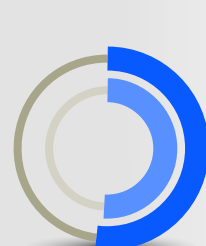
49% Among those currently working (39%), 49% took days off work due to their NET



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

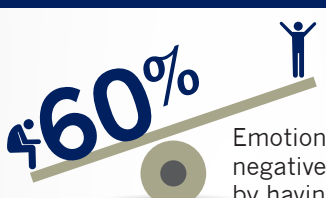
50%

of patients reported their finances were negatively impacted by their NET



Increased time and money 52% and money 51% spent on travel to and from medical appointments

### Emotional Health



60% Emotional health is negatively affected by having NETs



58% worry about uncertainty of the future



52% deal with significant stress and anxiety levels



43% are unable to participate in activities they used to enjoy



39% feel confused about the management of their disease

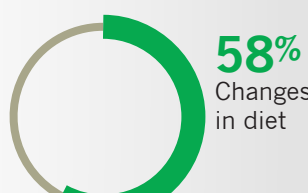
### Lifestyle

Lifestyle is negatively affected by having NETs

54% ability to participate in leisure activities

70% overall energy levels

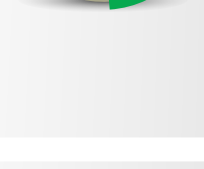
Patients with NETs made several lifestyle changes as a result of their disease, including:



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

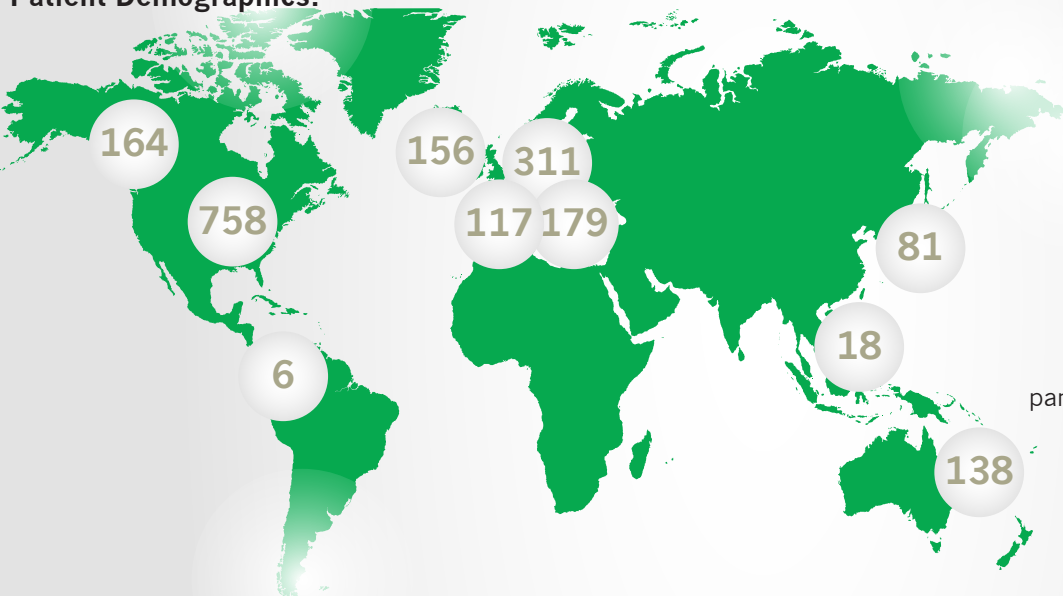
INCA member organizations invited patients with NETs to participate in the 25-minute online anonymous survey via flyers, website postings, emails and social media channels



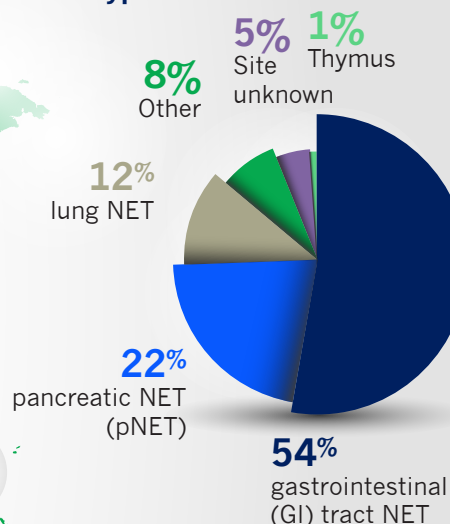
Paper surveys were developed in several languages and distributed at patient group meetings and via healthcare professionals to reach patients without access to the internet

### Participant Patient Population

#### Patient Demographics:



#### Type of NET:



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%)



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