

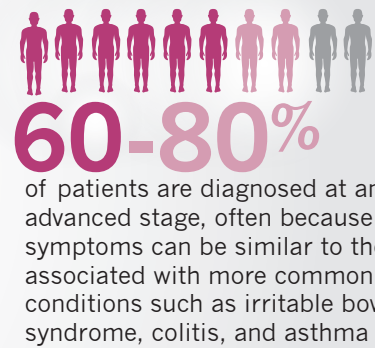
First Global Survey of Patients with Neuroendocrine Tumors (NETs)

Quality of life results from largest-ever survey of NET patients

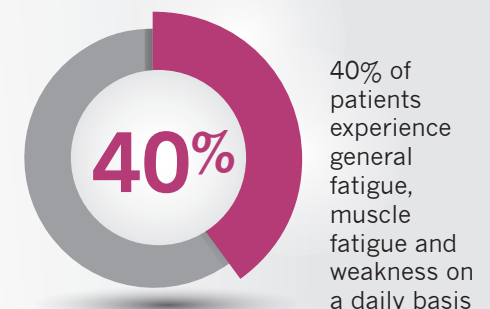
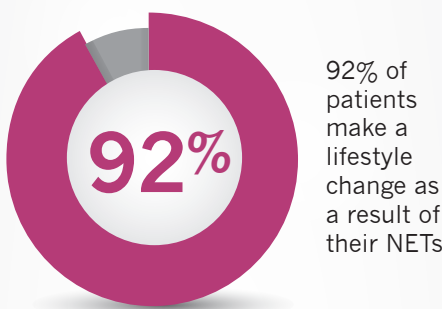
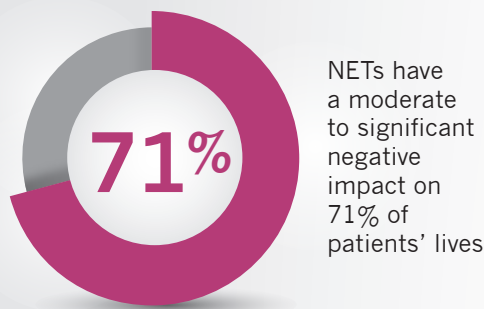
A Collaboration between the International Neuroendocrine Cancer Alliance (INCA) and Novartis

About NETs

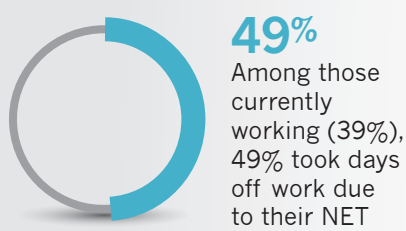
Neuroendocrine tumors (NETs) are rare tumors that can produce and secrete a variety of hormones that regulate bodily functions



Quality-of-Life Results

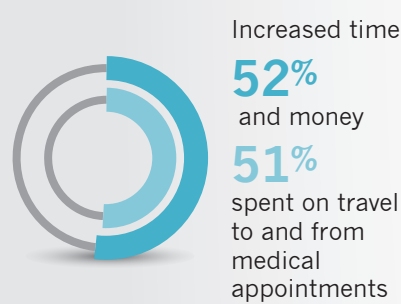


Work and Finances

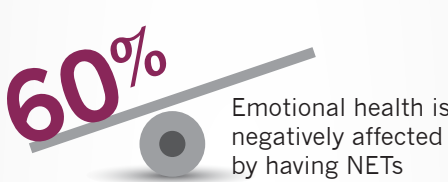


Among patients not working or unemployed due to medical disability (22%), 82% had stopped working as a result of their NET

50% of patients reported their finances were negatively impacted by their NET



Emotional Health



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



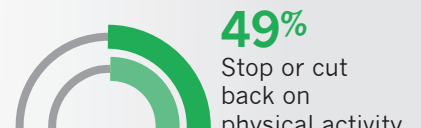
Lifestyle

Lifestyle is negatively affected by having NETs

70% overall energy levels

54% ability to participate in leisure activities

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



Overall, patients feel that...



• improved access to NET treatments (46%)



• increased awareness of NETs (42%)



• improved access to a NET medical team (43%)



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

...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 NET patients, and provide insights and learnings among countries and regions to advance NET care on a global level.



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

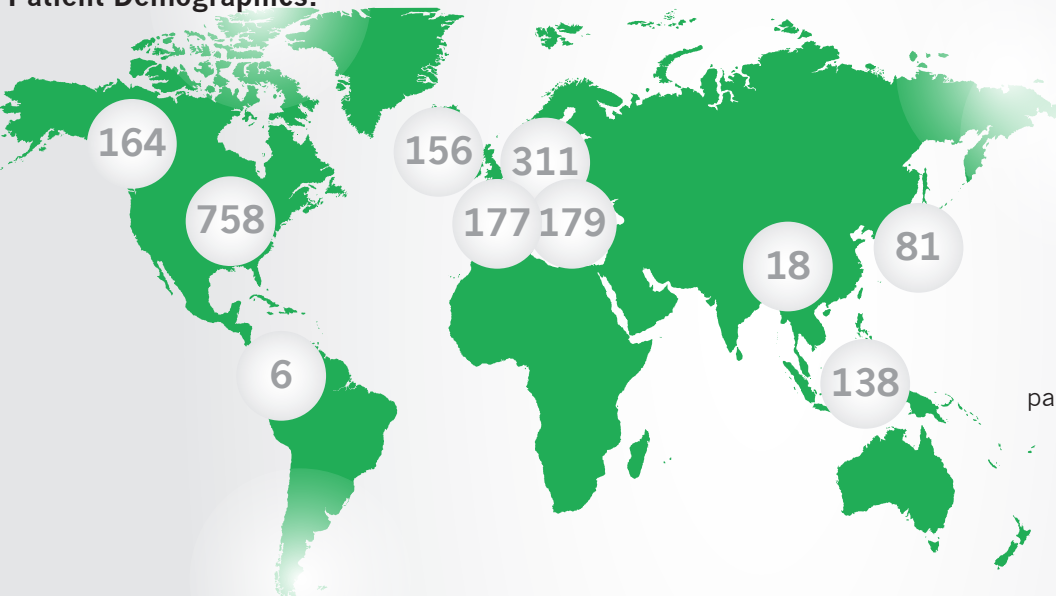
INCA member organizations invited patients with NETs to participate in the 25-minute online anonymous survey via flyers, website postings, emails and social media channels



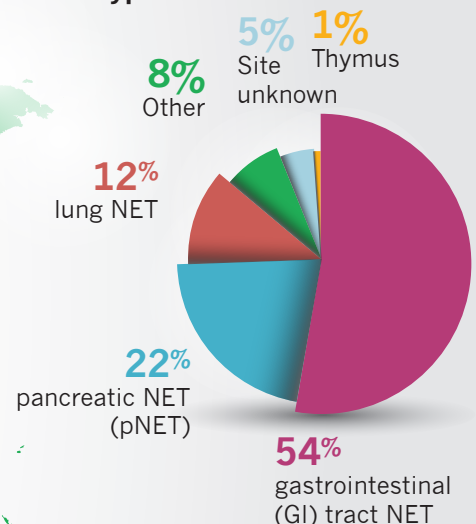
Paper surveys were developed in several languages and distributed at patient group meetings and via healthcare professionals to reach patients without access to the internet

Participant Patient Population

Patient Demographics:



Type of NET:



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