

First Global Survey of Patients with Neuroendocrine Tumors (NETs) US quality-of-life results from largest-ever survey of NET patients

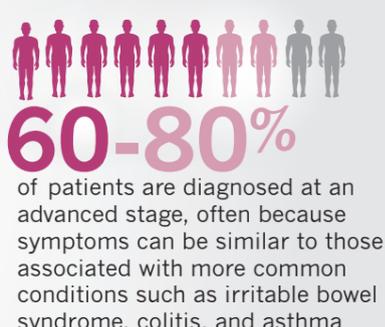
A Collaboration between the International Neuroendocrine Cancer Alliance (INCA) and Novartis



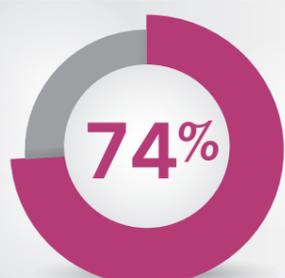
Participating US advocacy groups from INCA are the Carcinoid Cancer Foundation (CCF) and Caring for Carcinoid Foundation (CFCF)

About NETs

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



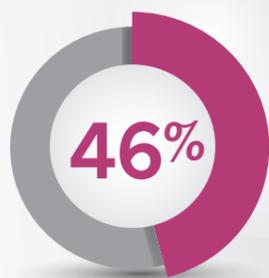
Quality-of-Life Results



NETs have a moderate to significant negative impact on 74% of patients' lives



94% of patients make a lifestyle change as a result of their NETs



46% of patients experience general fatigue, muscle fatigue and weakness on a daily basis

Work and Finances



Among those currently working (42%), 62% took days off work due to their NET



Among patients not employed or not able to work due to medical disability (25%), 79% had stopped working as a direct result of their NET

59%

of patients reported their finances were negatively impacted by their NET



Increased time and money spent on travel to and from medical appointments

Emotional Health

58%

Emotional health is negatively affected by having NETs



worry about uncertainty of the future



deal with significant stress and anxiety levels



are unable to participate in activities they used to enjoy



feel confused about the management of their disease

Lifestyle

Lifestyle is negatively affected by having NETs

71% overall energy levels

54% ability to participate in leisure activities

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

64% Changes in diet

57% Stop or cut back on physical activity

46% Stop or cut back on social life

Overall, patients feel that...



• improved access to NET treatments (51%)



• increased awareness of NETs (42%)



• improved access to a NET medical team (45%)



• a better understanding of how to manage disease-related symptoms (44%)

...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**

In the US, **758** patients with NET took part in the Global survey, representing **39%** of the total survey population of 1928 patients.



The survey was made available in 8 languages, and participating INCA member organizations invited patients with NETs to participate in the 25-minute online anonymous survey via flyers, website postings, e-mails, and social media channels



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

US Participant Patient Population

