

# 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.<sup>1</sup>



## Methodology<sup>1</sup>

The survey was fielded from

**February–May 2014**



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.

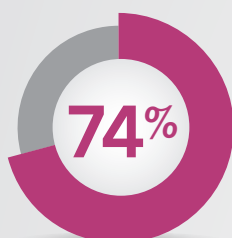


**1,928**  
patients from

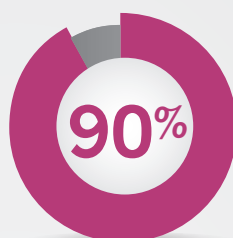


**12**  
countries took  
the survey

## Quality-of-life results<sup>1</sup>



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



90% of patients made a lifestyle change as a result of their NETs

## Work and finances<sup>1</sup>



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



82% of patients not working or unemployed due to medical disability had stopped working as a result of their NET\*

\* Asked only to patients who were not currently employed or not able to work because of medical disability (30%).

**49%**

of patients reported their finances were negatively impacted by their NET

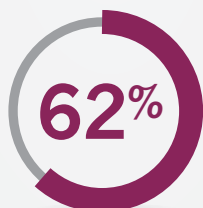
## Emotional health<sup>1</sup>

**68%**

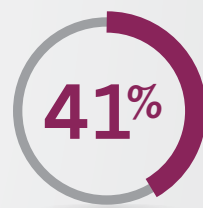
Emotional health was negatively affected by having NETs



worried about uncertainty of the future



dealt with stress and anxiety



were unable to participate in activities they used to enjoy

## Lifestyle<sup>1</sup>

Lifestyle was negatively affected by having NETs.

**71%**

overall energy levels

**51%**

ability to participate in leisure activities

Patients with NETs made several lifestyle changes as a result of their disease, including:<sup>1</sup>



changed their diet



stopped or cut back on physical activity

**42%**  
stopped or cut back on social life

## Overall, patients felt that...



• increased awareness of NETs (43%)<sup>1</sup>



• more support for dealing with the mental health consequences related to NETs (42%)<sup>1</sup>



• materials that can help explain NETs to family and friends (32%)<sup>1</sup>

...would help them to live a better life