**BACKGROUND**

Neuroendocrine tumors (NETs) are a diverse group of rare neoplasms arising from neuroendocrine cells that can have a heterogeneous disease course and may poorly be understood by many patients and health care providers (HCPs). NETs are classified into two major categories: gastroenteropancreatic (GEP) NETs and pulmonary NETs, the latter being a more homogeneous category.

- GEP NETs include tumors originating from the GI tract and the pancreas, which are classified based on histology as well as clinical outcomes.
- Pulmonary NETs are less common and may present with a wider variety of symptoms.

**METHODS**

From February through May 2014, patients with NETs participated in a 25-minute survey conducted by INCA. The survey was conducted as an equal collaboration between INCA and Novartis, and the data were analyzed by TNS, a global market research company. INCA is a network of 17 independent charitable organizations and patient groups from around the world that focus on NETs. A cross-sectional comparative analysis of 196 patients with NETs in Norway compared with those in the United States demonstrated significant differences between the populations in terms of NET diagnosis, treatment, and outcomes.

**RESULTS**

The large global survey of patients with NETs demonstrated that NETs have a large impact on patients’ daily lives, including emotional health, interactions with friends and family, ability to care for household, and vitality HRQoL subscales.

**LIMITATIONS**

- The large global NET survey had several important limitations that may have impacted the results:
  - A patient-reported design was employed without independent verification, leading to potential recall bias.
  - The survey did not utilize standardized, validated quality-of-life assessment instruments.
  - Response rates were not available for each country, limiting the generalizability of the results.
  - Respondents were more likely to be highly engaged and motivated care givers, including female patients and/or those with a more positive prognosis.

**CONCLUSIONS**

The large global survey of patients with NETs demonstrated that NETs have a large impact on patients’ daily lives, including emotional health, interactions with friends and family, and ability to care for household. NET medical teams, particularly oncologists and nurse/oncology hematologists, can play a crucial role in enhancing patient understanding and confidence. More awareness of NETs is needed in general (42%) and more awareness of how to manage treatment-related NETs is needed (37%/41%).

**REFERENCES**

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**Figure 1. Patients participating in the global NET patient survey.**

**Figure 2. Time to NET diagnosis.**

**Figure 3. Patient reported negative impact of NETs on quality of life.**

**Figure 4. Negative impact of NETs on different aspects of life.**

**Figure 5. Support provided by HCPs.**

**Figure 6. HCP understanding of how NETs affect patients’ lives.**

**Figure 7. Patients who had to stop working as a direct result of NETs.**

**Figure 8. Patient knowledge regarding NETs.**

**Figure 9. Patient access to and usefulness of NET resources.**

**Figure 10. Sources of NET information used by patients.**