BACKGROUND
Neuroendocrine tumors (NETs) are a diverse group of one to five neoplasms arising from neuroendocrine cells that have a heterogeneous disease course and remain poorly understood by many patients and health care providers (HCPs).

METHODS
- A cross-sectional comparative analysis of 196 patients with NETs in Norway demonstrated significantly lower HRQoL scores in patients with NETs versus the general Norwegian population, particularly with regard to symptoms of diarrhoea and fatigue.
- A cross-sectional comparative analysis of 196 patients with NETs in Norway demonstrated significantly lower HRQoL scores in patients with NETs versus the general Norwegian population: lower scores were found for the general physical health, physical role, bodily pain, vitality, social functioning, and emotional role domains (p < 0.05).
- The survey to patients with NETs has not been previously published; only a few small qualitative studies have been published to date (N < 20).
- INCA is a network of 17 independent charitable organizations and patient groups from 14 countries around the world. Novartis Pharmaceutical Corporation collaborated with INCA on the global survey to gather data about the NET patient experience from multiple countries, with the goal of capturing individual patient experiences and identifying gaps between countries and regions to help improve NET awareness and care.

RESULTS
Demographics
- A total of 1928 patients with NETs were recruited from 12 countries in the Americas, Asia, Europe, and Oceania (Figure 1).

Figure 1. Countries participating in the global NET patient survey.

Impacts of on-patients’ daily lives
- 72% of patients were employed full or part time or were self-employed, 31% were retired.
- 60% of patients reported being diagnosed <5 years ago (Figure 2), including overall energy levels (70%); their emotional health (60%); and their relationships with their family (59%); and their social life (46%).

Figure 2. Time since diagnosis.

Support received from medical team
- Patients felt well supported by their medical team, particularly by their oncologists (77%) and gastroenterologists (77%), although some reported lower support from other HCPs, including nurses and oncologists/hematologists.

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

This global NET patient 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 tools.
- Patients were connected to patient advocacy groups online, which may have elevated patient expectations.
- Patients may have been more likely to be highly engaged and motivated care sought, including female patients and/or those with a favorable prognosis.

LIMITATIONS
This global NET patient survey had several important limitations that may have impacted 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 tools.
- Patients were connected to patient advocacy groups online, which may have elevated patient expectations.
- Patients may have been more likely to be highly engaged and motivated care seekers, including female patients and/or those with a favorable 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 ability to perform household tasks or travel. The survey also identified gaps in NET medical treatment, particularly oncologists/hematologists and nurse practitioners.

How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?
- How do patients feel about information and support tools available?