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# Neuroendocrine tumor (NET) Impact on Quality of Life (QOL)— Patient Experience From the First Global NET Patient Survey: A Collaboration Between the International Neuroendocrine Cancer Alliance (INCA) and Novartis Pharmaceuticals

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**Background:** NETs remain poorly understood due to their rare presentation and heterogeneous nature. Although incidence is increasing, only a few small qualitative studies document the NET patient experience. INCA and Novartis collaborated on the first global NET patient survey. Here we present patient quality of life (QOL) data.

**Methods:** A 25-minute online anonymous survey of NET patients from the Americas, Europe, Asia, and Oceania was conducted by Hall & Partners Health (February–May 2014) regarding NET diagnosis, disease impact/management, medical team interactions, knowledge/awareness levels, and information needs. Statistical differences are noted at the  $P < 0.05$  level.

**Results:** 1928 NET patients from >12 countries (n=758 US; n=164 Canada) participated. Globally, NET types included gastroenteropancreatic (76%), lung/thymic (13%), and other/unknown (13%). Most patients had G1/G2 (58%) functional (44%) disease. 71% reported a moderate to significant negative impact of NETs on QOL including overall energy levels (70%) and emotional health (60%). Patients made several lifestyle and work changes, including diet modifications (58%), time/money for medical appointments (52%/51%), limited physical activity/social life (49%/43%), and days off work (49%). Of 22% of participants not employed because of medical disability, 82% stopped working due to their NETs. In the US, significantly more patients reported NET-related financial challenges versus the global population (59% vs 50%). US/Canadian patients reported higher levels of anxiety/stress (58%/62% vs 52%) and confusion about their NET management (47%/42% vs 39%) versus global patients. Patients felt that improved access to a NET medical team/treatments (43%/46%), increased awareness of NETs (42%), and a better understanding of how to manage disease/treatment-related symptoms (41%/37%) would help them live better with NETs.

**Conclusion:** The first global NET patient survey demonstrates the significant emotional and financial burden of NETs and identifies improvements to help enhance patient care, including NET medical team/treatment access, NET awareness, and information regarding symptom management.