

Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor (NET) Patients (SCAN) - The Role of the Family Doctors in NET Diagnostics and Care

Authors:

Dirk Van Genechten, Mark McDonnell, Dermot O'Toole, Harjit Singh, Jie Chen, James R. Howe, Simron Singh, Catherine Bouvier, Christine Rodien-Louw, Sugandha Dureja, Simone Leyden, Teodora Kolarova

Corresponding author: Dirk Van Genechten

Background

Neuroendocrine tumors (NETs) are complex neoplasms with increasing incidence and prevalence worldwide, affecting various organs, but most commonly the gastrointestinal tract. SCAN assessed global provision of NET healthcare. This analysis focused on the role family doctors (FDs) play in early detection of NETs.

Methods

During Sept-Nov 2019, NET patients and healthcare professionals (HCPs) from medical specialties relevant to NETs completed an online survey, available in 14 languages, disseminated via social media and NET patient group networks.

Results

2359 NET patients/carers and 436 HCPs from 68 countries across 6 continents participated. HCPs were most often medical oncologists (25% [108/436]), gastrointestinal specialists (15% [66/436]). FDs were 7% [30/436]. NETs were most often gastroenteropancreatic (GEP NET; 71% [1670/2359]). Almost half of patients were initially misdiagnosed (44% [1043/2359]). Incorrect diagnoses included: gastritis (GEP NET: 40% [313/727]; irritable bowel syndrome (GEP NET: 39% [284/727]); asthma (lung NET: 45% [49/108]). Mean time to NET diagnosis was 5 years [N=1042]. Almost half of patients (46% [1077/2359]) were diagnosed with stage IV NETs or had metastases at time of diagnosis. HCPs who suggested the diagnostic test were mostly gastroenterologists (20% [480/2359]) and FDs (19% [456/2359]), according to patients. For HCPs, most often oncologists (85% [291/343]) and pathologists (82% [282/343]) were involved in diagnostics. FDs' role in diagnostics was ranked low (38% [130/343]) by HCPs, while 86% [11/13] of FDs stated to be more involved. Low awareness of key diagnostic tools registered among FDs: MRI (63% [19/30]), Chromogranin A (37% [11/30]), Gallium 68 DOTANOC PET CT (37% [11/30]).

Conclusion

Delayed NET diagnosis is a global challenge. Family doctors play a leading role in NET diagnostics together with gastrointestinal specialists. The role of family doctors in diagnosis of NETs has considerable room for improvement as does awareness of diagnostic tools. SCAN represents the biggest global compendium of NET data.