Abstract D31: Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor (NET) Patients (SCAN) – NET Experts & NET Healthcare

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Background:
- Neuroendocrine tumors (NETs) are rare and complex neoplasms with increasing incidence and prevalence worldwide.1
- SCAN assessed global provision of NET diagnostics and treatment in terms of:
  - Awareness
  - Quality of servicing
  - Availability
  - Affordability
- This analysis focused on global delivery of healthcare to NET patients – Advanced Economies (AE) vs. Emerging and Developing Economies (EDE).

Methods:
- During Sept-Nov 2019, NET patients and healthcare professionals (HCP) completed a self-report online survey.
- The survey was disseminated via social media and NET patient groups’ and medical societies’ networks.
- The survey was available in 14 languages: Arabic, Bulgarian, English, German, Dutch/Flemish, French, Japanese, Hindi, Italian, Mandarin (Chinese), Portuguese, Russian, Spanish, and Swahili.

Results:
- There were 2795 respondents from 68 countries across 6 continents.
- AE NET patients/carers were 88% [2076/2359], EDE were 12% [283/2359].
- HCPs were evenly spread: 51% AE [221/436] vs. 49% EDE [215/436].
- Only half of patients overall (53% [1255/2359]) had visited a NET specialist within 12 months and this percentage was much lower for EDE - 40% (112/283) vs AE – 55% (1143/2076) p<0.0001.
- Patients travelled further to see NET specialists in EDE (1032 [1578] km) than in AE (181 [496] km, p<0.001).

Figure 1: Access to care for NET patients

![Figure 1: Access to care for NET patients](image)

- Multidisciplinary team (MDT) care was accessible to slightly above a third of NET patients globally (33% [769/2359]), more so in AE (34% [706/2076]) vs EDE (22% [63/283]) p<0.0001.
- The average evaluation score provided by NET patients to the healthcare received in their country was 3.5 globally, 3.6 in AE, while 2.5 in EDE on a 5-point Likert scale.
- HCPs’ and NET patients’ scores were aligned: 3.9 as per AE HCPs [94% [208/221]], vs. 2.6 by EDE HCPs [68% [190/283]].
- NET patients that used NET specialist consultations evaluated their healthcare quality received at 3.8 [1230/2359] vs significantly lower score of 3.2 [1037/2359] given by those that did not use NET specialist consultations.

Future directions
- Improving awareness of NETs and tackling accessibility and affordability issues are key to improving NET care across AE and EDE.

Conclusions
- Global access to NET specialists and MDTs is limited, with big gaps between AE and EDE.
- The overall rating of the quality of healthcare received is slightly above average, however access to NET specialists significantly improves healthcare quality scores.

Reference

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