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Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor (NET) Patients (SCAN) – USA and Canada vs Global Diagnosis of NETs

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BACKGROUND: Neuroendocrine tumors (NETs) are rare and complex neoplasms with increasing incidence and prevalence worldwide. SCAN assessed global delivery of healthcare to NET patients.

METHODS: During Sept-Nov 2019, 2359 NET patients and 436healthcare professionals (HCPs) from 68 countries completed an online self-report survey, available in 14 languages, disseminated via social media and NET patient group networks.

RESULTS: 23% NET patients/carers were from United States (US) [511/2359], 9% from Canada (CA) [208/2359]. Almost half of patients were initially misdiagnosed with other conditions (Global: 44% [1043/2359]), US: 48% [245/511]; CA 46% [96/208]). Mean time to correct diagnosis was globally 5 years, 6 in US and 7 in CA. Almost half of patients globally, and a significantly higher proportion in US and CA, were diagnosed with stage IV NETs or had metastases at the time of diagnosis (Global: 46% [1077/2359]; US: 52%[266/511]; CA: 52%[109/208] ($p<0.0001$). The diagnostic tools that most often led to correct diagnosis were biopsy (Global: 59% [1392/2359]; US: 55% [281/511]; CA 57%[119/208]) and CT scan, significantly higher in US and CA (Global: 46%[/2359], US 55%[/511], CA 64%[/208]($p<0.0001$). Diagnostic tools used: MRI (Global: 23% [543/2359], US 25%[128/511], CA 31%[65/208] ($p<0.0001$), Octreotide Scan (Global: 15% [354/2359], US 13%[66/511], CA 30% [62/208] ($p<0.0001$), Ultrasound (Global: 17% [401/2359], US 16%[82/511], CA 26%[54/208] ($p<0.0001$); Gallium 68-DOTA PET CT had significantly lower usage both in US and CA (Global: 18% [425/2359], US 13%[66/511], CA 4%[8/208] ($p<0.0001$).

CONCLUSION: Misdiagnosis is a global challenge for NETs that likely leads to poorer patient outcomes. Significantly more patients are diagnosed with Stage IV NETs in US and Canada, which may be associated in part with higher rates of performing CT and MRI and less DOTA-PET.

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