

Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumour (NET) Patients (SCAN) – Australia and New Zealand (Oceania) vs Global Diagnosis of NETs

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Background

Neuroendocrine tumours are less common and complex neoplasms with increasing incidence and prevalence worldwide. SCAN, developed by the International Neuroendocrine Cancer Alliance (INCA), assessed global delivery of healthcare to NET patients. This assessment looks at the diagnosis and access of diagnostics and treatments from Oceania (Aust & NZ) data compared to Global data.



Methods

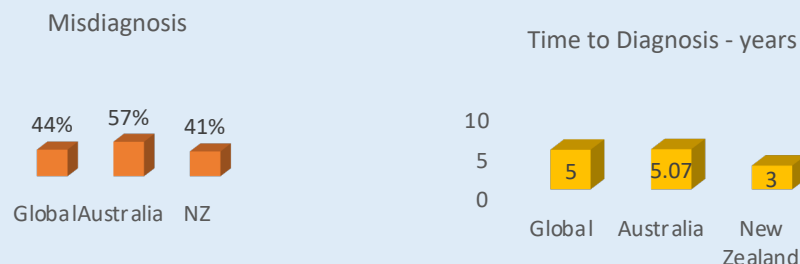
During Sept-Nov 2019, 2359, NET patients and 436 healthcare professionals (HCPs) from 68 countries completed an online survey, available in 14 languages, which was disseminated via social media and NET patient group networks.



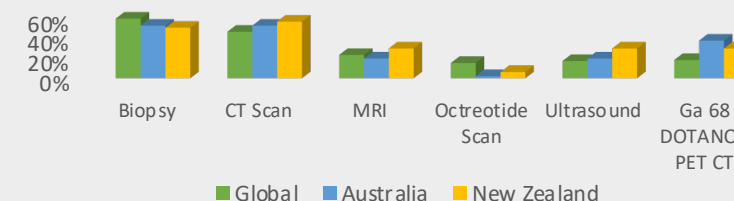
Results

Diagnosis

7% NET patients/carers were from Australia (Aust) [166/2359], 1.5% from New Zealand (NZ) [34/2359] with a combined 8.5% [200/2359]. Almost half of patients were initially misdiagnosed with other conditions - Global: 44% [1043/2359], Oceania 50% [100/200]. Again, about half of the patients globally, and a higher proportion in Oceania were diagnosed with NET metastases at time of diagnosis - Global: 49.6% [1155/2359], Oceania 58.2% [116/200] and the most common condition initially given prior to correct diagnosis was IBS – Global 33% [778/2359] and Oceania 50% [100/200].



Diagnostic Tools



Diagnostic and Monitoring Tools

The diagnostic tools that most often led to correct diagnosis were biopsy -Global: 59% [1392/2359]; Oceania 51.5% [103/200] and CT scan - Oceania 52.5% [104/200], Global 46% [1085/2359]. Significant is access as a diagnostic tool to Gallium 68 PET in Oceania 35.9% [72/200] to Global 18% [424/2359] and availability as an ongoing monitoring tool, Oceania 88% [176/200] compared with Global 68% [1604/2359]. Access to FDG PET as a diagnostic tool is again higher in Oceania 20.7% [40/200] compared with Global 13% [306/2359] and usage as an ongoing monitoring tool – Oceania 28.1% [56/200] compared with Global 14.9% [353/2359]

Treatment

With regards to access to treatments such as PRRT, availability is significant in Oceania 62.2% [124/200] and Aust 74.7% [119/162] compared with Global 52.3% [1226/2359], but the number to have actually received PRRT treatment was only Oceania 13.8% [28/200] and Global 11% [259/2359].

Conclusions

Misdiagnosis is a global challenge for NETs that leads to poorer patient outcome. The major issue is the lack of awareness of NETs and their symptoms. Nuclear medicine plays a significant role for NET patients, not only in diagnosis, monitoring but also treatment. Availability and usage of key imaging (Gallium 68 PET) and treatments (PRRT) is higher in Oceania compared with Global, thanks to the ongoing advocacy of the medical and patient community.