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The Role of NET Specialists in Diagnostics and Treatment – Comparison Global vs USA in 2019 – 2025

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BACKGROUND

This analysis assesses changes in NET (neuroendocrine tumor) specialist involvement in the patient care pathway over the six-year period 2019–2025, in the USA and globally.

METHODS

SCAN (Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumour Patients) evaluates NET healthcare delivery trends, with baseline data collected in 2019 and follow-up in 2025. Available in 14 languages in 2019 and 15 in 2025, the survey was disseminated by International Neuroendocrine Cancer Alliance (INCA) and its partner organizations. A total of 2,359 and 2,764 NET patients completed the online self-reported survey in 2019 and 2025 respectively, including 511 and 360 patients from the USA.

RESULTS

Over two-thirds of patients were aware of NET specialists in both cohorts and survey years – globally (73.1%/2,359; 75.1%/2,764;) and in the USA (71.4%/511; 69.4%/360) with no significant change over the six-year period.

Approximately half of NET patients reported consulting a NET specialist in the past 12 months – this percentage increased both globally (53.2%/n=2,359 vs. 57.2%/n=2,764, $p<0.05$) and in the USA (47.2%/n=511 vs. 51.4%/n=360)

The misdiagnosis burden improved significantly, with multiple prior misdiagnoses before NET diagnosis declining from 36.2% (n=511) in 2019 to 26.1% (n=360) in the USA and from 30.5% (n=2,359) to 25.3% (n=2,764) globally ($p<0.05$). The percentage of patients diagnosed

at a hospital without a NET specialist declined in the USA (42.3%/n=511; 36.1%/n=360;), following the global trend (41%/n=2,359; 34.6%/n=2,764).

NET specialist involvement in diagnostics increased significantly globally (21.6%/2,359 vs. 26.6%/2,764, p<0.05), but it remained stable in the USA (11.5%/511 vs. 13.9%/360, p<0.05 vs. global). NET specialist involvement in treatment increased significantly globally for about half of all NET patients (46.2%/2,359 vs. 50.9%/2,764, p<0.05), while it remained stable and significantly lower in the USA than the global rate (42.3%/511 vs. 44.1%/360, p<0.05 vs. global). NET specialist involvement in ongoing monitoring remained unchanged in both cohorts yet significantly lower in the USA: globally for about half of all NET patients (49.5%/2,359 vs. 53.1%/2,764) compared to the USA (43.4%/511 vs. 45.3%/360, p<0.05 vs. global). NET specialist participation in multidisciplinary team (MDT) increased significantly globally (41.5%/2,359 vs. 46.2%/2,764, p<0.05), with increase reported in the USA, while still significantly below the global rate (33.5%/511 vs. 39.2%/360, p<0.05 vs. global).

CONCLUSIONS

Between 2019 and 2025, NET specialist involvement in diagnostics, treatment, monitoring, and MDT management in the USA remained significantly below global rates. These findings underscore the need to strengthen specialist-led care pathways in the USA.

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