

Authors: Mark McDonnell¹, Teodora Kolarova², Catherine Bouvier³, Marianne Pavel⁴, Harjit Singh⁵, James Howe⁶, Simron Singh⁷, Dermot O’Toole⁸, Dirk Van Genechten⁹, Elyse Gellerman¹⁰, Sugandha Dureja¹¹, Simone Leyden¹², Christine Rodien-Louw¹³

¹NET Patient Network, Dublin, Ireland; ²INCA, Boston, US; ³Neuroendocrine Cancer UK, Leamington Spa, UK; ⁴Department of Endocrinology, Friedrich Alexander University Erlangen-Nuremberg, Erlangen, Germany; ⁵Prince Court Medical Centre, Kuala Lumpur, Malaysia; ⁶University of Iowa Carver College of Medicine, Iowa City, US; ⁷Sunnybrook Odette Cancer Centre, University of Toronto, Toronto, Canada; ⁸National Centre for Neuroendocrine Tumours, St. Vincent’s University and Department of Clinical Medicine, St. James Hospital and Trinity College, Dublin, Ireland; ⁹vzw NET & MEN Kanker Belgium, Kortrijk, Belgium; ¹⁰NET Research Foundation, Boston, US; ¹¹CNETS India, New Delhi, India; ¹²NeuroEndocrine Cancer Australia, Blairgowrie, Australia; ¹³APTED, Lyon, France



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:



- This analysis focused on global delivery of healthcare to NET patients – Advanced Economies (AE) vs. Emerging and Developing Economies (EDE).

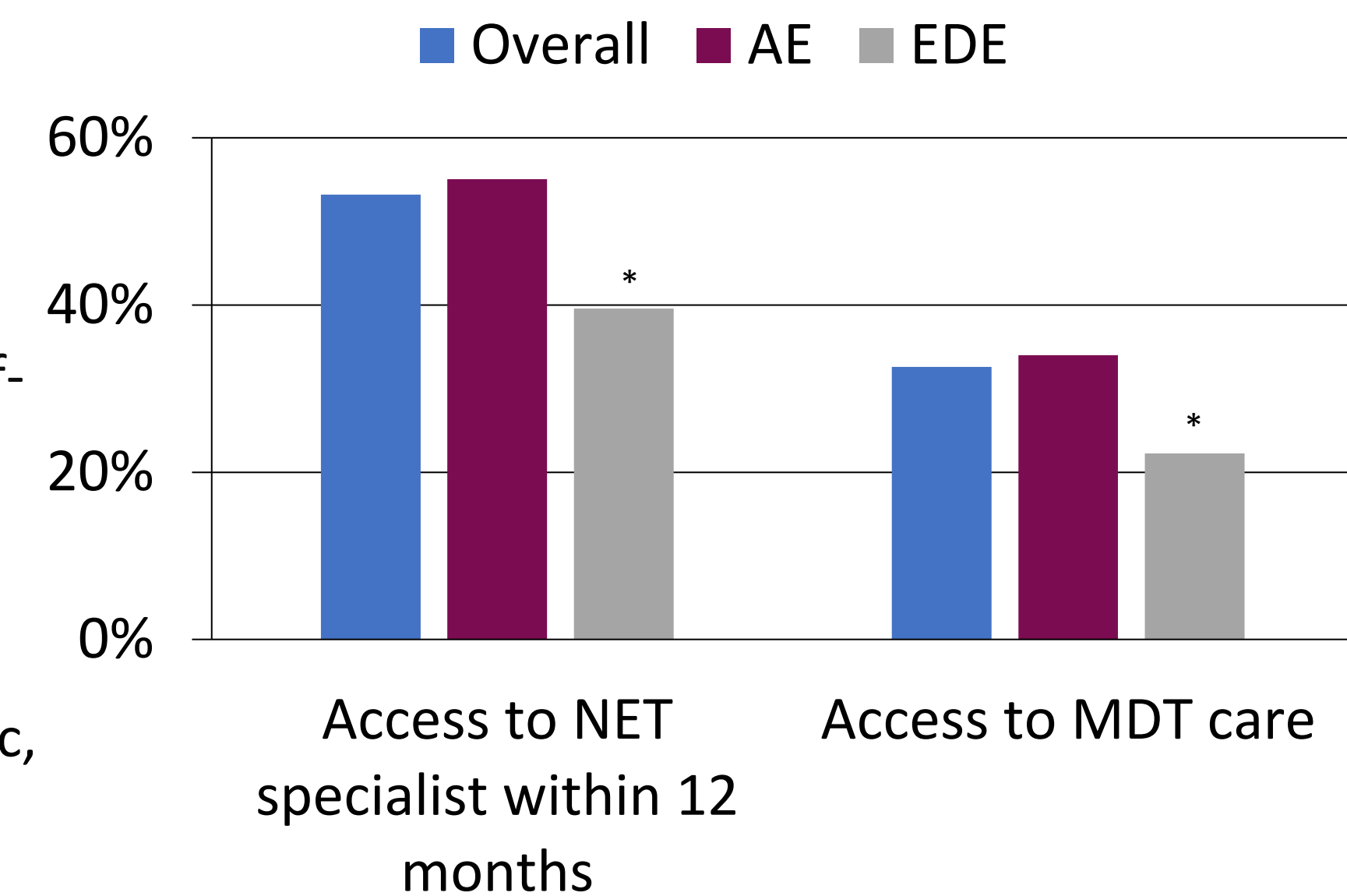
Methods:

- 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:

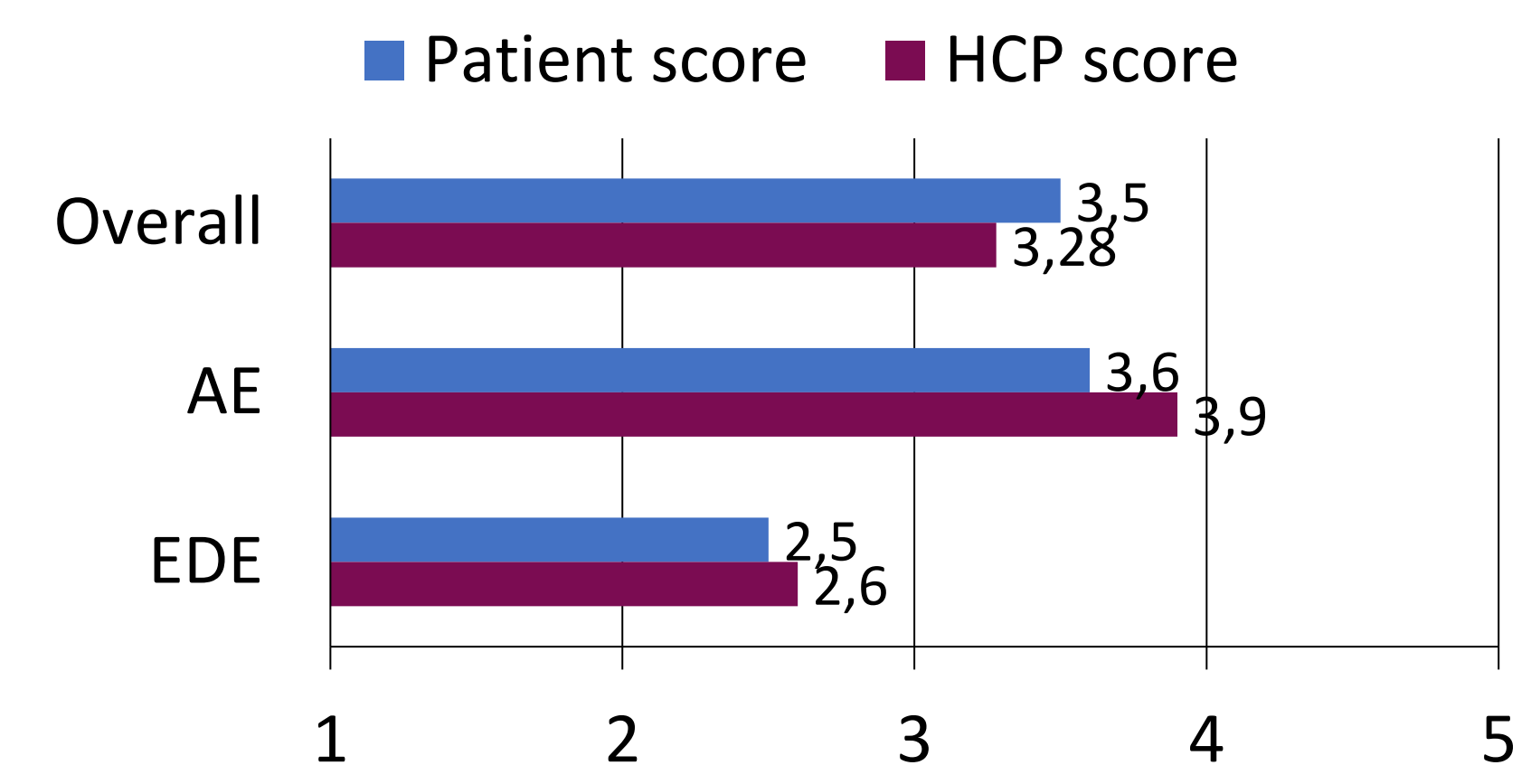
- There were 2795 respondents from 68 countries across 6 continents.
- AE NET patients/carers were 88% [2076/2359], EDE were 12% [283/2359].
- HCPs were evenly spread: 51% AE [221/436] vs. 49% EDE [215/436].
- Only half of patients overall (53% [1255/2359] had visited a NET specialist within 12 months 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



*p<0.0001 vs AE. AE: Advanced Economies; EDE: Emerging and Developing Economies; MDT: multidisciplinary team; NET: neuroendocrine tumor.

Figure 2: Average score by NET patients and HCPs for healthcare received



AE: Advanced Economies; EDE: Emerging and Developing Economies; HCP: healthcare professional. Scores for care rated on a Likert scale of 1–5. (1=poor; 5=excellent)

- 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.

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.**

Future directions

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

Reference

1. Dasari A, et al. JAMA Oncol 2017;3:1335-42.

Acknowledgements

INCA would like to thank all its members as well as its partners: ENETS (European Neuroendocrine Tumor Society), NANETS (North American Neuroendocrine Tumor Society), APNETS (Asia-Pacific Neuroendocrine Society), CommNETs (Commonwealth Neuroendocrine Tumor Group), JNETS (Japan Neuroendocrine Tumor Society), CSNET (Chinese Study Group for Neuroendocrine Tumors), UICC (Union for International Cancer Control), EURORDIS (European Organisation for Rare Diseases), NORD (National Organization for Rare Disorders) and European Cancer Organisation and many others for their instrumental support of this global effort.

This study was industry sponsored.

Strategen Ltd, Winchester, UK provided editorial support to the authors.