

Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor Patients (SCAN): The Diagnostic Process of GEP NETs in Asia, Europe, North America and Oceania

Teodora Kolarova¹, Mark McDonnell², Catherine Bouvier³, Elyse Gellerman⁴, Dirk Van Genechten⁵, Sugandha Dureja⁶, Christine Rodien-Louw⁷, Simone Leyden⁸

¹INCA, Boston, US, ²NET Patient Network, Dublin, Ireland, ³Neuroendocrine Cancer UK, Leamington Spa, UK, ⁴NET Research Foundation, Boston, US, ⁵vzw NET & MEN Kanker Belgium, Kortrijk, Belgium, ⁶CNETS India, New Delhi, India, ⁷APTED, Lyon, France, ⁸NeuroEndocrine Cancer Australia, Blairgowrie, VIC, AU

INTRODUCTION

- Neuroendocrine tumors (NETs) are rare and complex neoplasms, affecting various organs, but most commonly the gastrointestinal tract.¹
- NET incidence and prevalence is increasing worldwide making it one of the fastest growing classes of cancer.¹
- The International Neuroendocrine Cancer Alliance (INCA) consists of 28 patient advocacy and research groups and supports NET patients (and their families) by advocating on their behalf to improve time to diagnosis, care and research.

BACKGROUND

- The Survey of Challenges in Access to Diagnostics and Treatment for NET Patients (SCAN) measured healthcare delivery to neuroendocrine tumor patients globally.
- This analysis focused on the diagnosing process in gastroenteropancreatic (GEP) neuroendocrine tumor (NET) patients in a comparative perspective – Asia (AA), Europe (EU), North America (NA) and Oceania (OA).

METHODS

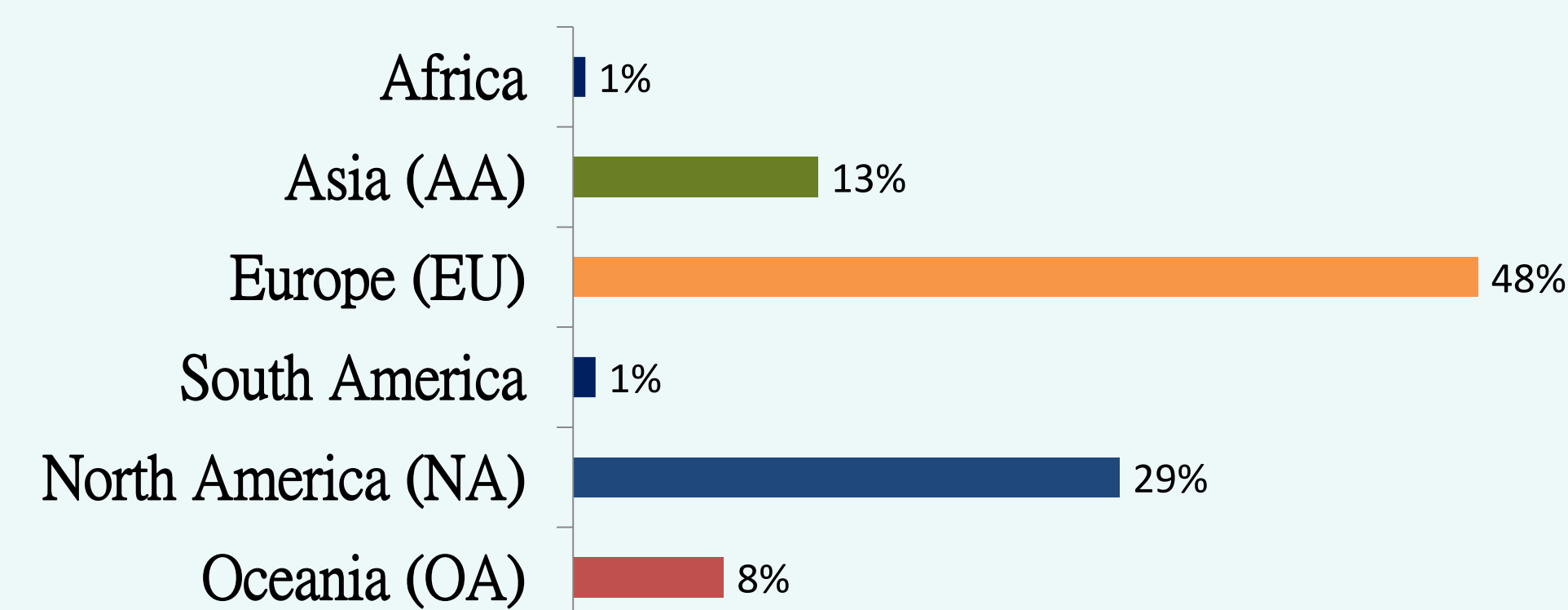
- During Sept-Nov 2019, NET patients and healthcare professionals (HCPs) completed an online self-reported survey.
- The survey was disseminated via social media and NET patient groups and medical society networks.
- The survey was available in 14 languages:
 - Arabic, Bulgarian, English, German, Dutch/Flemish, French, Japanese, Hindi, Italian, Mandarin (Chinese), Portuguese, Russian, Spanish, and Swahili.
- On average, NET patients took 20 minutes and HCPs 11 minutes to complete the questionnaire.

RESULTS

Participant Characteristics

- There were 2795 respondents from 68 countries.
- 1670 NET patients (71% of the global sample, N=2359) were GEP NET patients: 48% from EU (802/1670), NA – 29% (485/1670), AA – 13% (211/1670), OA – 8%, (141/1670).

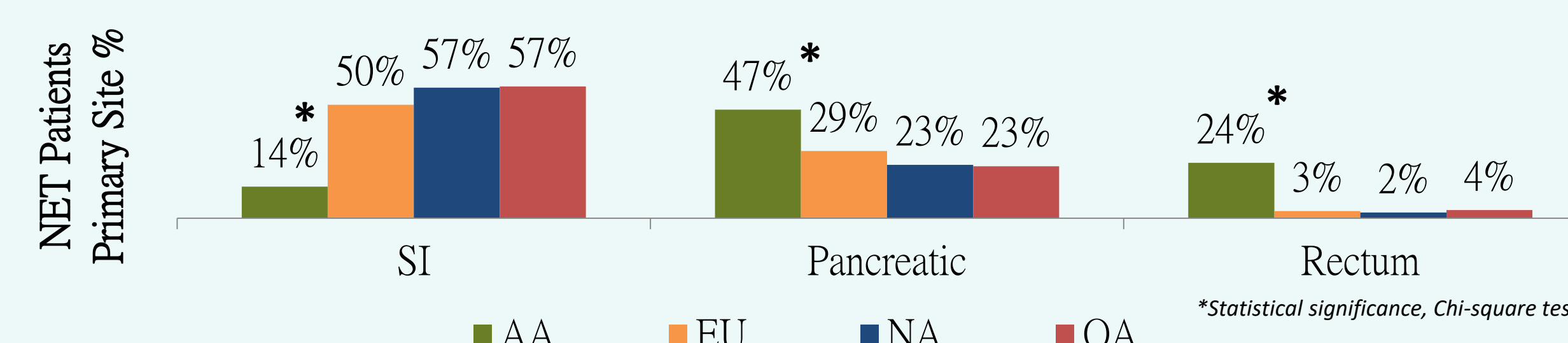
Figure 1: GEP NET Patient Sampling Profile by Geo Areas



NET Type & Stage

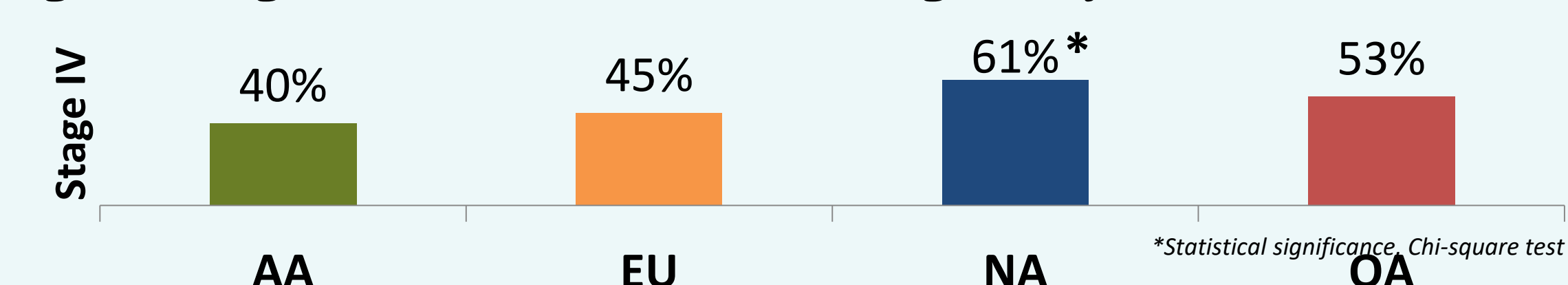
- Primary GEP NETs were predominantly small intestinal (SI) and pancreatic (PNET), with similar proportions in EU, NA and OA, significantly more PNET vs. SI in AA (Figure 2)

Figure 2: Most Common Primary NET Type by Geo Area



- Over 40% of GEP NET patients had stage IV NETs at the time of diagnosis, significantly higher in NA vs other regions (Figure 3).

Figure 3: Stage IV GEP NET at the time of diagnosis by Geo Areas

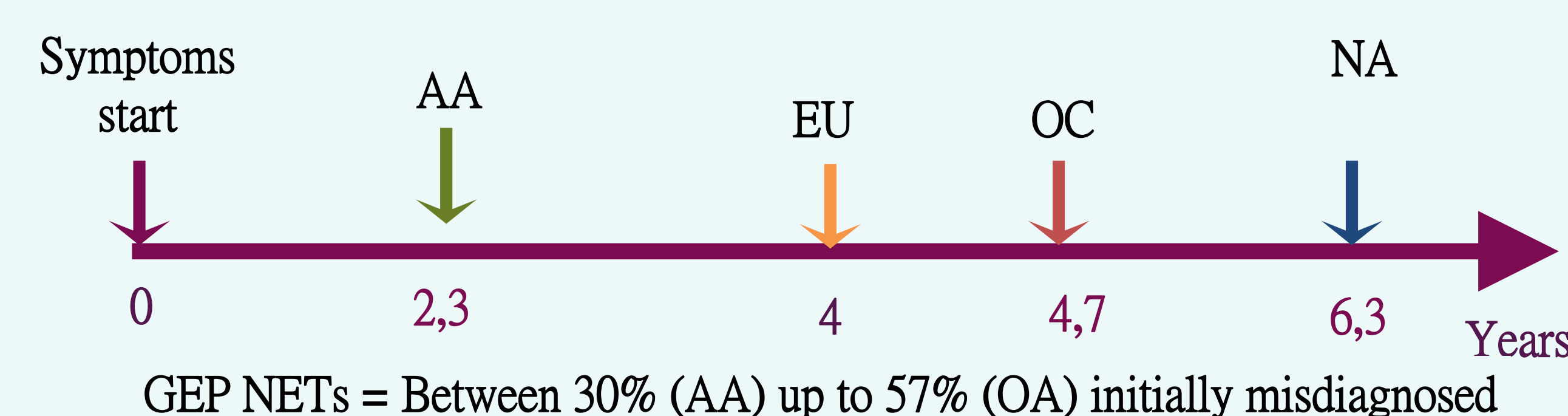


RESULTS continued

GEP NET Diagnosing and Misdiagnosing

- After initial symptoms and tests, GEP NET was the first diagnosis for 30% of patients from AA and EU GEP NET patients, 28% from NA and 24% from OA.
- The majority of patients were misdiagnosed at least once but most commonly multiple times: (AA, 33%, 70/211; EU, 43%, 342/802; NA, 45%, 219/485; OA, 57%, 80/141).
- Most common misdiagnoses were gastritis/other digestive (AA, 53%, 37/70; EU, 38%, 131/342; NA, 47%, 102/219; OA, 44%, 35/80) and irritable bowel syndrome (AA 16%, 11/70; EU, 35%, 119/342; NA, 48%, 104/219; OA, 56%, 45/80).
- 30% from AA, 26% from EU, 25% from NA and only 18% from OA had their diagnosis made incidentally during testing for another condition.
- Mean time to correct NET diagnosis was five (SD 5) years, shortest in AA (2.3 years, N=70), EU (4 years, N=341), 6.4 years in NA (N=219), OA (4.7, N=80) (Figure 4).

Figure 4: Mean time to correct NET diagnosis and proportion of misdiagnosis



Medical Specialist Involvement in the Diagnosing Process

- On average three HCPs were involved in the diagnosing process with no difference among the regions
- Leading diagnosticians were gastroenterologists: AA (34%); EU, (27%), NA (24%); OA (16%), and GPs: AA (10%); EU (20%); NA (21%); OA (28%), less in AA.

CONCLUSIONS

- SCAN represents the biggest global compendium of data about NETs.
- Since over 40% of GEP NET patients present with metastatic disease, delayed NET diagnosis is a critical challenge that needs to be overcome to improve patient outcomes.
- The route to correct NET diagnosis is lengthy, with mean time to correct diagnosis being 5 years, while detection is often incidental.
- Increasing the number of knowledgeable HCPs, especially gastroenterologists and GPs, must be a key priority in order to drive forward improvements in global NET care.

REFERENCES

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

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