

# Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor (NET) Patients (SCAN) – Healthcare Quality Evaluation

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## INTRODUCTION

- Neuroendocrine tumors (NETs) are rare and complex neoplasms, affecting various organs, but most commonly the gastrointestinal tract.<sup>1</sup>
- NETs incidence and prevalence is increasing worldwide making it one of the fastest growing classes of cancer.<sup>1</sup>
- The International Neuroendocrine Cancer Alliance (INCA) consists of 26 patient advocacy and research groups and supports NET patients (and their families) by advocating on their behalf to improve diagnosis, care and research.

## OBJECTIVE

- SCAN assessed global delivery of NET diagnostics and treatment in terms of:

Awareness Availability Quality Affordability

- This analysis focused on the quality of global delivery of NET healthcare.

## METHODS

- During Sept-Nov 2019, NET patients and healthcare professionals (HCPs) completed an 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.
- On average, NET patients took 20 minutes and HCPs 11 minutes to complete the questionnaire.

## RESULTS

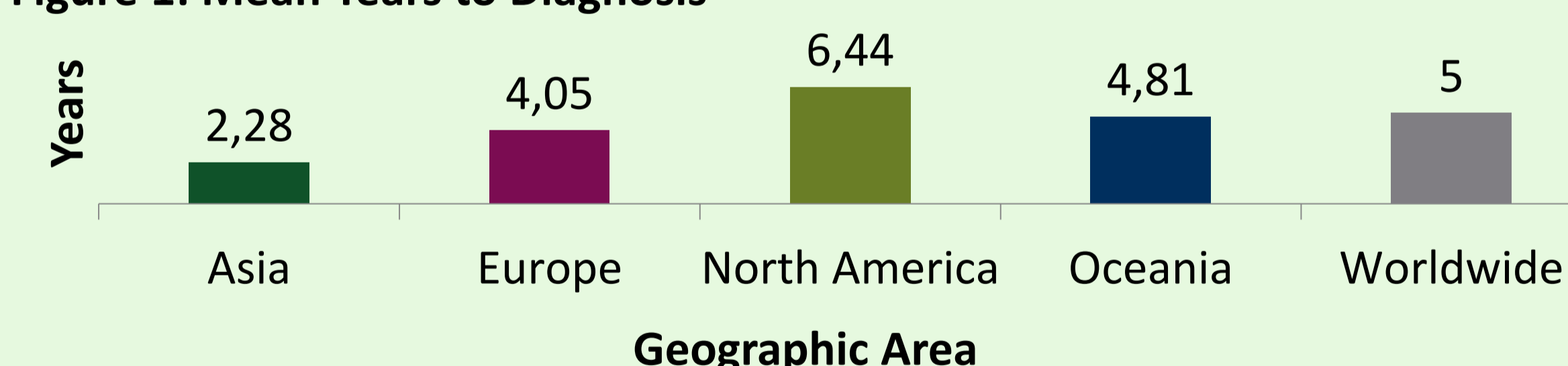
### Participant Characteristics

- There were 2795 respondents from 68 countries
  - 436 HCPs of which medical oncologists comprised 24% [103/436]
  - 2359 NET patients/carers: Europe (47% [1102/2359]); North America (31% [727/2359]); Asia (12% [280/2359]); Oceania (9% [200/2359]); South America & Africa (2% [50/2359]).

### Diagnosis

- Almost half (44% [1042/2359]) of patients were initially misdiagnosed.
- Almost half (46% [1077/2359]) of patients had stage IV NETs or had metastases at diagnosis.
- Mean time to diagnosis was 5 years, lower in Asia and higher in North America (t-test, p<0.0001, Figure 1).

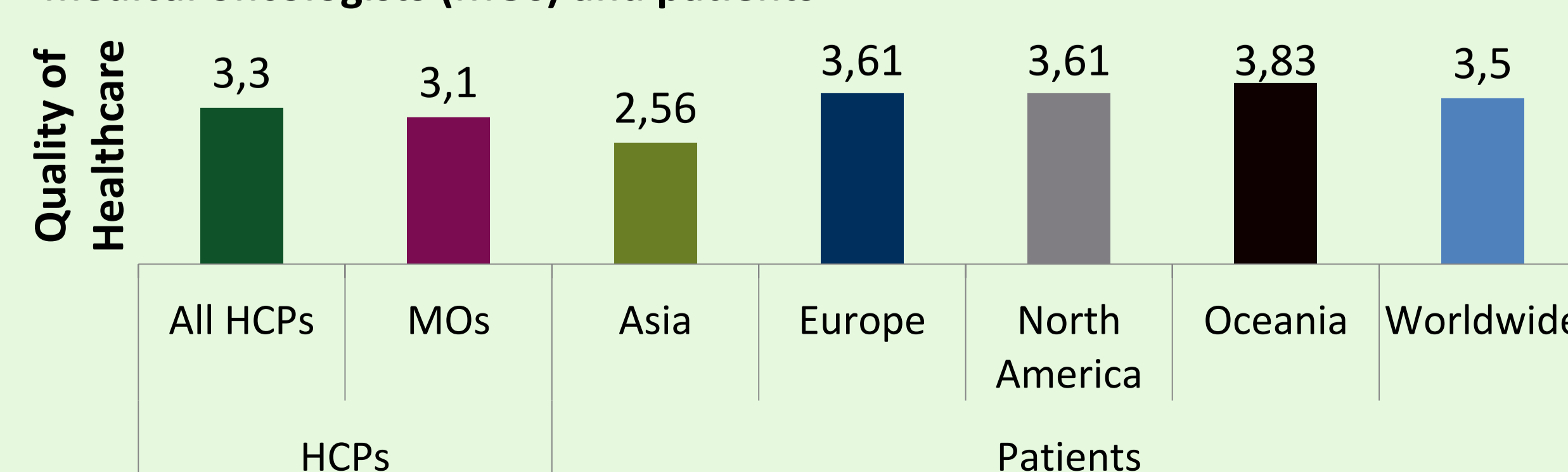
Figure 1: Mean Years to Diagnosis



### Quality of Care

- The quality of healthcare provided was evaluated by NET patients at 3.5 and HCPs/medical oncologists at 3.3/3.1 (5-point Likert scale).

Figure 2: Mean Healthcare Quality Score by health care professionals (HCPs), medical oncologists (MOs) and patients

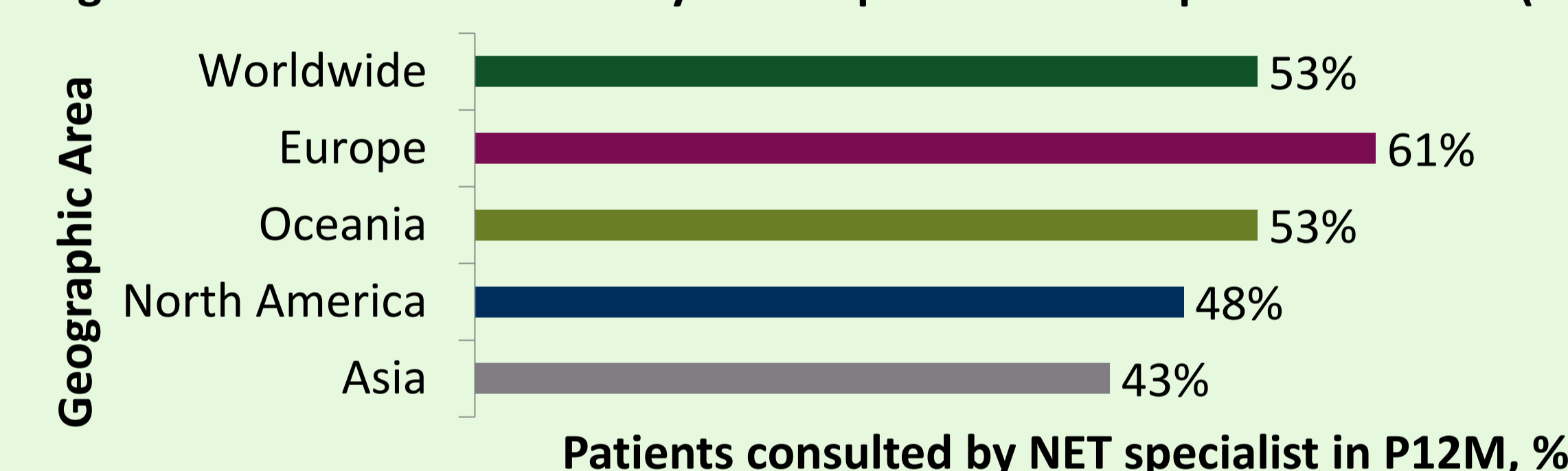


## RESULTS continued

### Healthcare Services

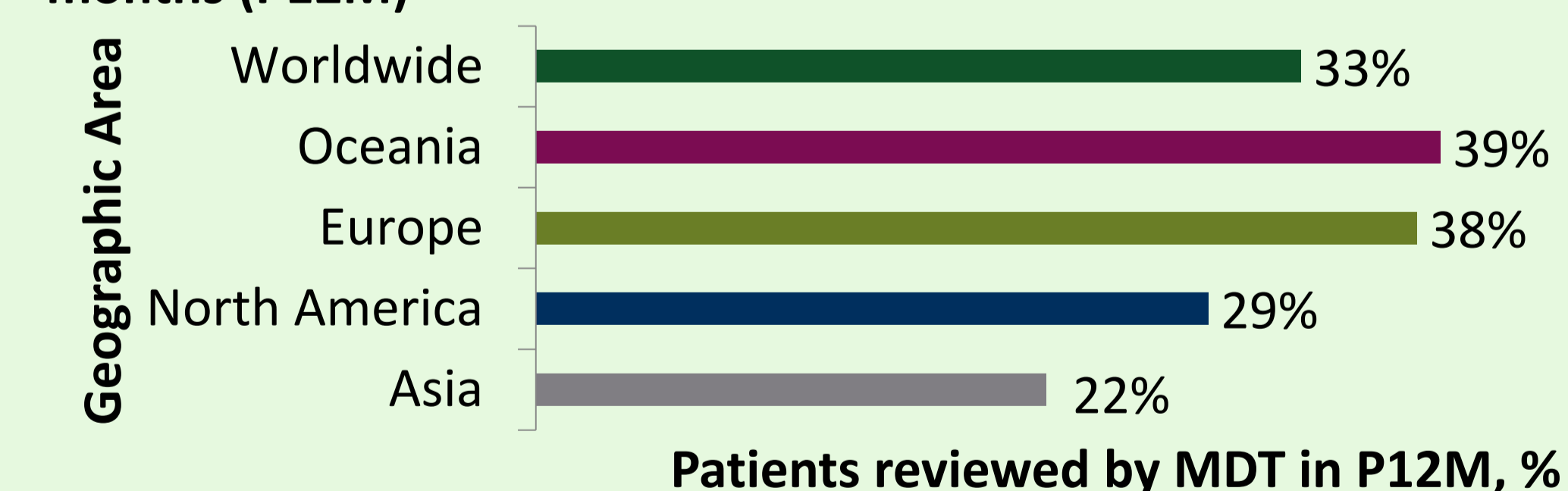
- Slightly over half of NET patients were consulted by a NET specialist in the past 12 months (P12M), with the highest rates in Europe and Oceania (All: 53% [1255/2359]; Europe: 61% [668/1102], North America: 48% [350/727], Asia: 43% [120/280], Oceania: 53% [105/200], p<0.0001, Chi-squared, Figure 3).

Figure 3: Patients consulted by a NET specialist in the past 12 months (P12M)



- Only one third of patients were reviewed by a multidisciplinary team in P12M, less in North America and Asia (All: 33% [769/2359]; Europe: 38% [415/1102], North America: 29% [210/727], Asia: 22% [62/280], Oceania: 39% [77/200], p<0.0001).

Figure 4: Patients reviewed by a multidisciplinary team (MDT) in the past 12 months (P12M)



- A medical oncologist was the most involved HCP in follow-up in 60% of NET patients, particularly in North America and Oceania (Europe 54% [593/1102] vs. North America 75% [548/727] vs. Asia 34% [95/280], vs. Oceania 75% [150/200] p<0.0001).

### Recommendations

- The most common recommendation to improve NET diagnosis and management, given by medical oncologists, was 'better access to NET experts/specialist centers (75% [77/103]).

## CONCLUSIONS

- SCAN represents the biggest global compendium of data about NETs extant.
- Delayed NET diagnosis remains a global challenge.
- The delivery of healthcare to NET patients is in need of significant improvement globally to ensure proper and timely diagnosis and treatment.
- SCAN results will help drive forward optimal care and referral pathways to achieve the goal of earlier diagnosis.
- Improving access to NET specialists and multidisciplinary care should be a priority for healthcare systems.
- This survey further contributes to positioning NET research on an equal footing with other cancers of similar prevalence.

## REFERENCES

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

## ACKNOWLEDGEMENTS

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- The lead author has nothing to declare.