1113P: Care for Neuroendocrine Tumor Patients, Monitored by Medical Oncologists: **Comparative Data From Europe vs. North America**

¹INCA, Boston, US, ²NET Patient Network, Dublin, Ireland, ³Neuroendocrine Cancer UK, Leamington Spa, UK, ⁴Department of Endocrinology, Friedrich Alexander University Erlangen, Germany, ⁵Prince Court Medical Centre 39, Jalan Kia Peng, Kuala Lumpur, Malaysia, ⁶University of Iowa Carver College of Medicine, Iowa City, US ⁷Sunnybrook Odette Cancer Centre, University of Toronto, Canada ⁸National Centre for Neuroendocrine Tumours, St. Vincent's University and Department of Clinical Medicine, St. James Hospital and Trinity College, Dublin, Ireland ⁹The First Affiliated Hospital, Sun Yat-sen University, Guangdong, China ¹⁰NeuroEndocrine Cancer Australia, Blairgowrie, VIC, AU, ¹¹NET Research Foundation, Boston, US, ¹²CNETS India, New Delhi, India, ¹³APTED, Lyon, France, ¹⁴vzw NET & MEN Kanker Belgium, Kortrijk, Belgium

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 27 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 medical care received by NET patients who most often visited a medical oncologist (MO) comparing Europe (EU) and North America (NA).

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 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.

Teodora Kolarova¹, Mark McDonnell², Catherine Bouvier³, Marianne Pavel⁴, Harjit Singh⁵, James R. Howe⁶, Simron Singh⁷, Dermot O'Toole⁸, Jie Chen⁹, Simone Leyden¹⁰, Elyse Gellerman¹¹, Sugandha Dureja¹², Christine Rodien-Louw¹³, Dirk Van Genechten¹⁴

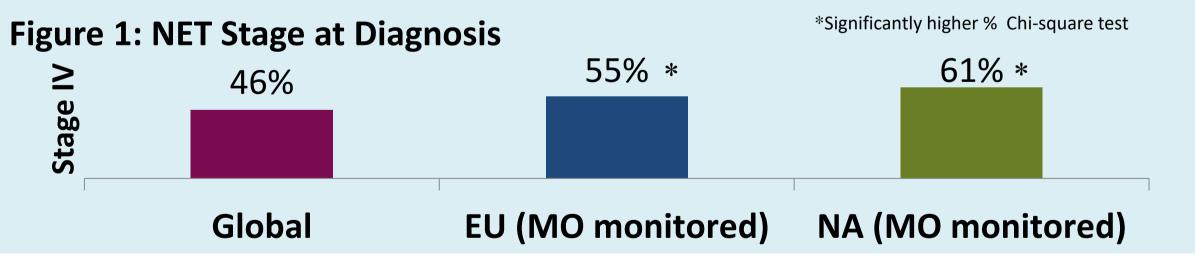
RESULTS

Participant Characteristics

- There were 2795 respondents from 68 countries.
- 1016 NET patients (43% of global sample, N=2359) reported a medical oncologist (MO) as the HCP most often visited for ongoing monitoring.
- 80% of these patients were from two geographic areas: Europe (EU) [40%, 409/1016] including 22 countries and North America (NA) [40%, 410/1016] (US and Canada).

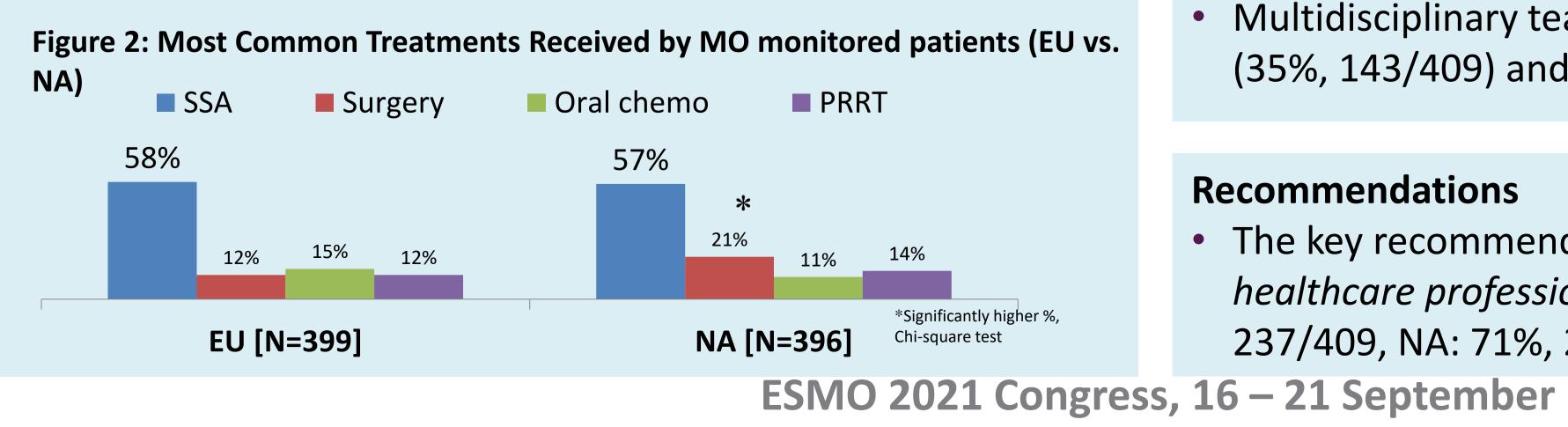
NET Type & Stage

- Primary NETs for this sub-group were most often GEP NETs (74%, 754/1016, EU: 76%, 312/409; NA 72%, 296/410), which was similar to data from all countries (71%, 1670/2359).
- 55% from EU (223/409) and 61% from NA (252/410) had stage IV disease at diagnosis – both significantly higher than the percentage reported by patients globally (46%, 1077/2359, p<0.0001).(Fig. 1)



Treatments Received

The most commonly used treatments for this sub-group of patients were somatostatin analogues (SSA), surgery (higher in NA), oral chemotherapy and PRRT (Fig. 2)



RESULTS continued

Ongoing Monitoring Tools

- The most common monitoring tools used by MOs in both the EU and NA were conventional imaging and chromogranin A (Figure 3).
- ⁶⁸Gallium DOTA-PET CT, other blood tests (fasting serum) glucose, fasting gastrin, glucagon, VIP) and urine 5-HIAA were also used significantly more frequently in NA.

Figure 3: Most Common Monitoring Tools Usage (EU vs. NA)

■ EU [N=395] ■ NA [N=407]

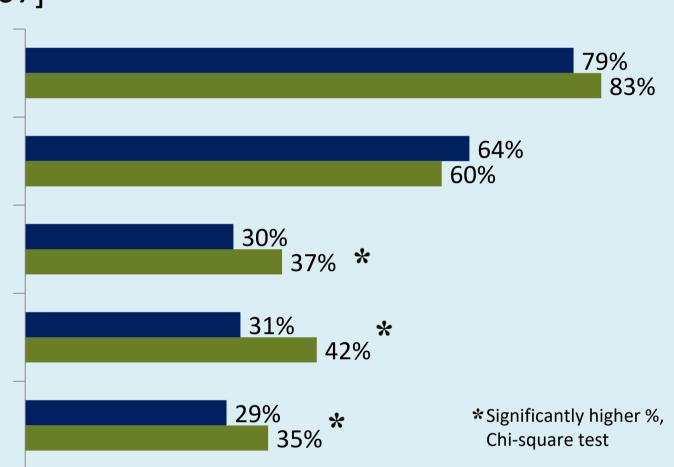
Conventional imaging

Chromogranin A

68 Gallium DOTA-PET CT

other blood tests





Medical Specialist Involvement

- MOs were the most often visited specialists in the follow-up of these patients, although 2.98 HCPs on average were involved.
- After removing MOs, these were most often GPs/family doctors (EU, 48%, 197/409; NA: 44%, 181/410) and nurses (EU: 27%, 111/409; NA: 22%, 91/410).
- In cases where a third HCP was involved, in EU this was most often a nuclear medicine specialist (23%) or a radiologist (20%), while in NA this was a surgeon (25%).
- Multidisciplinary teams (MDT) were rarely used both in EU (35%, 143/409) and NA (32%, 131/410).

Recommendations

• The key recommendation from patients was to have *more* healthcare professionals knowledgeable in NETs (EU: 58%, 237/409, NA: 71%, 291/410 p<0.0001).

Cancer Alliance 2021

International

Neuroendocrine

CONCLUSIONS

- SCAN represents the biggest global compendium of data about NETs.
- Since over half of patients present with metastatic disease, delayed NET diagnosis is a critical challenge that needs to be overcome to improve patient outcomes.
- Medical oncologists were found to be the leading HCPs for ongoing monitoring for almost half of NET patients globally.
- Data indicate significant differences in therapeutic and follow-up procedures and low usage of the multidisciplinary approach even in the EU and NA, the leading geographic areas for NET medical care.
- A global standard for NET monitoring and higher expertise in NETs among HCPs are needed.

REFERENCES

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), CSNETS (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 ECCO (European Cancer Organisation) and many others for their instrumental support of this global effort.

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

FUNDING AND DISCLOSURE

- This study was sponsored by Ipsen, ITM and Novartis.
- The lead author is the Executive Director of the International Neuroendocrine Cancer Alliance, which receives funding from Ipsen, ITM, AAA and Novartis.

Correspondence should be sent to teodora.kolarova@incalliance.org