

# Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor (NET) Patients (SCAN) – UK and Ireland vs. Global Diagnosis of NETs

Catherine Bouvier<sup>1</sup>, Mark McDonnell<sup>2</sup>, Christine Rodien-Louw<sup>3</sup>, Dirk Van Genechten<sup>4</sup>, Simone Leyden<sup>5</sup>, Elyse Gellerman<sup>6</sup>, Sugandha Dureja<sup>7</sup>, Teodora Kolarova<sup>8</sup>

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

## INTRODUCTION

- Neuroendocrine tumors (NETs) are rare and complex neoplasms with increasing incidence and prevalence worldwide<sup>1</sup>

## OBJECTIVES

- SCAN assessed global delivery of healthcare to NET patients in terms of:

Awareness	Quality of care
Availability	Affordability

- Data on diagnosis of NETs in the United Kingdom (UK) and Ireland (IE) were analyzed and compared to global data

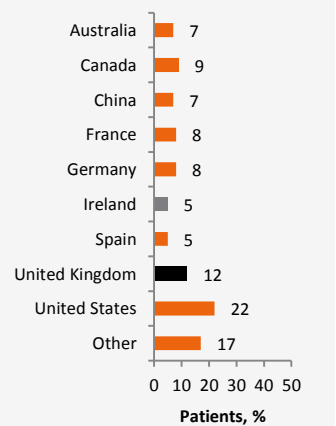
## METHODS

- During Sept-Nov 2019, NET patients and healthcare professionals (HCP) from 68 countries completed an online survey
- The survey, available in 14 languages, was disseminated via social media, NET patient groups' and medical societies' networks

## RESPONDENT CHARACTERISTICS

- Overall, 2795 participants responded: 2359 patients/carers; 436 HCPs
- 12% NET patients/carers were from UK (279/2359); 5% from IE (119/2359; Figure 1).

Figure 1: NET patients by geographic area

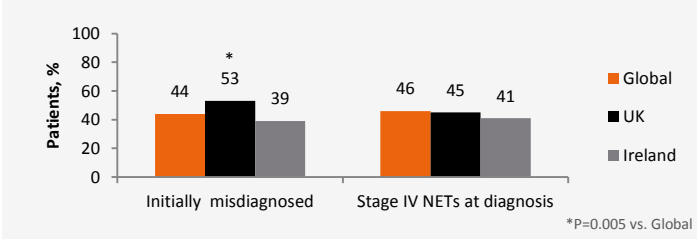


## RESULTS

### DELAYS IN DIAGNOSIS

- After initial symptoms and tests, NET was the first diagnosis for approximately one third of patients (Global: 27% [640/2359]; UK: 28% [79/279]; IE: 35% [41/119])
- Globally, 44% (1043/2359) of patients were initially misdiagnosed at least once with other conditions. Compared to globally, this figure was significantly higher in UK (53% [148/279]; P=0.005) and lower in IE (39% [46/119]; NS; Figure 2)
- Mean time to correct diagnosis for patients misdiagnosed was similar: Global: 4.75 years (N = 1043); UK: 4.4 (N=148); IE: 5.24 (N=46)
- Almost half of patients had stage IV NETs at diagnosis (Global: 46% [1077/2359]; UK: 45% [126/279]; IE: 41% [49/119]; Figure 2)

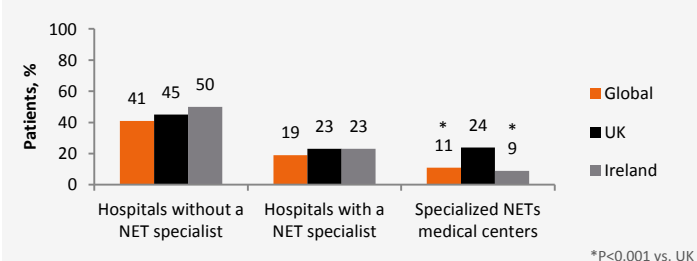
Figure 2: Misdiagnosis and staging of NETs



### RECEIVING A DIAGNOSIS

- Fewer than a quarter of patients globally and in the UK and IE received their NET diagnosis in a hospital with a NET specialist (Global: 19%; UK: 23%; IE: 23%; Figure 3)
- In the UK, every fourth NET patient received diagnosis in a medical center specialized in NETs (24% [68/279]), this ratio being significantly lower globally (11% [253/2359]) and in IE (9% [11/119]); P<0.001 for both comparisons; Figure 3)

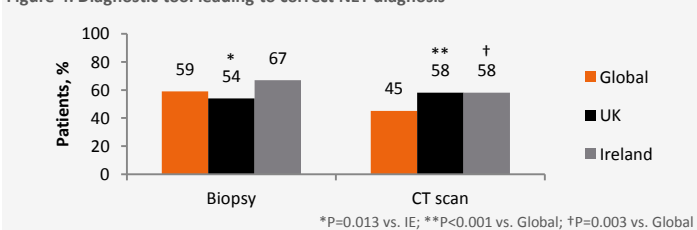
Figure 3: Type of hospital where NET diagnosis was received



### DIAGNOSTIC TOOLS

- The most common diagnostic tools that led to correct diagnosis were biopsy and CT scan (Figure 4)
- Globally, 59% (1392/2359) of patients were diagnosed correctly based on a biopsy (UK: 54% [150/279] vs. IE: 67% [80/119]; P<0.013). Compared to globally, a significantly higher proportion of patients in UK (p<0.001) and IE (P=0.003) were diagnosed correctly based on a CT scan (Figure 4).

Figure 4: Diagnostic tool leading to correct NET diagnosis



## CONCLUSIONS

- SCAN represents the largest global compendium of data about NETs extant
- Misdiagnosis and the extremely high proportion of NET patients diagnosed with stage IV, which is associated with poorer patient outcomes, remain global challenges
- The experiences of UK and Irish patients on their route to diagnosis is similar to that of patients surveyed worldwide
- Access to specialized NET centers should be improved for all NET patients and more HCPs knowledgeable in NETs are needed
- These results will help drive forward optimal care and referral pathways to achieve the goal of earlier diagnosis
- This survey further contributes to positioning NET research on an equal footing with other cancers of similar prevalence

## 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), CNETS (Chinese Neuroendocrine Tumor Society), 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. INCA would also like to thank its industry supporters: Ipsen, ITM and Novartis.

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

## FUNDING AND DISCLOSURES

This study was industry sponsored. The authors have nothing to declare.