# THE NET DIAGNOSTIC PROCESS AND THE ROLE OF GASTROINTESTINAL SPECIALISTS

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## INTRODUCTION

- Neuroendocrine tumors (NETs) are rare and complex neoplasms with increasing incidence and prevalence worldwide.[1]
- The **S**urvey of **C**hallenges in **A**ccess to Diagnostics and Treatment for **N**euroendocrine Tumor Patients (SCAN) assessed the delivery of healthcare to NET patients around the world.

## AIM

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


- This analysis focused on the NET diagnostic process and the role gastroenterologists play in it.

## METHOD

- During Sept-Nov 2019, NET patients and healthcare professionals (HCP) completed a self-reported online survey.
- The survey was disseminated via social media and through 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.
- 2359 NET patients and 436 HCPs from 68 countries responded.

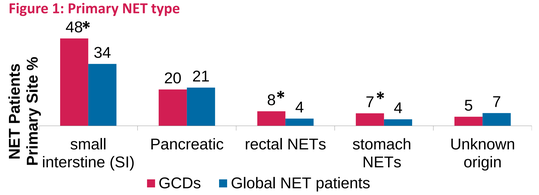
## RESULTS

### Participant Characteristics:

- Globally, primary NETs were most often gastroenteropancreatic (GEP; 71%, 1670/2359), 10% were lung NETs and 7% were NETs of unknown origin.
- The patient-reported route to correct NET diagnosis included consultations with more than one physician namely surgeons (46%, 1085/2359), medical oncologists (40%, 944/2359), gastroenterologists (39%, 922/2359) and general practitioners (GPs) or family doctors (39%, 922/2359).

**Every fifth** NET patient was diagnosed correctly by a gastroenterologist (20%, 480/2359).
The sub-group of patients where gastroenterologists suggested diagnostic tests that led to the correct diagnosis (Gastroenterologist Correct Diagnosis - GCD) were **GEP NETs in 96%** (435/480) **of the cases**.

**Figure 1: Primary NET type**

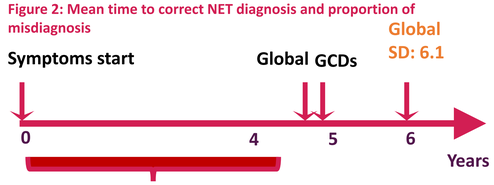



** GCDs statistically significantly higher vs. Global fraction, p<0.0001 by Chi-square*

### NET Diagnosing, Misdiagnosing and Staging:

- After initial symptoms and tests, NET was the first diagnosis for 28% of GCD patients (28%, 134/480) vs. 27% Global (640/2359).
- 44% of patients were initially misdiagnosed at least once with other conditions (GCD: 211/480, Global: 1043/2359).
- Most common misdiagnoses were Gastritis/Other digestive (52%, 110/211), or IBS (42%, 88/211).
- One quarter (GCD 26%, 125/480 vs. global 26%, 613/2359) had their diagnosis made incidentally during testing for another condition.

**Figure 2: Mean time to correct NET diagnosis and proportion of misdiagnosis**



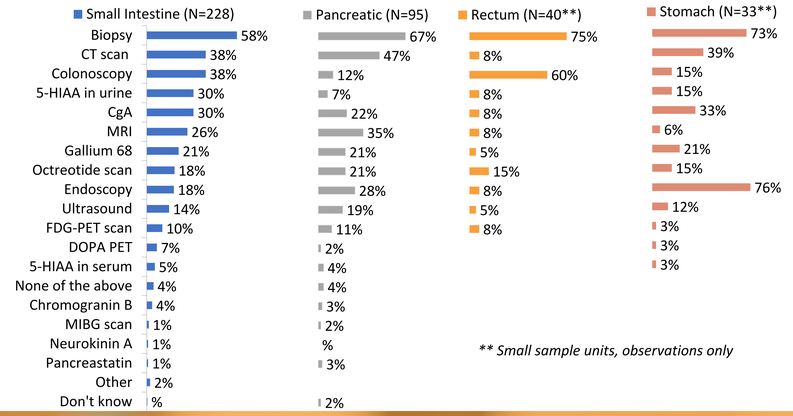

**GCDs = Global : 44% initially misdiagnosed**

- Mean time to correct diagnosis for misdiagnosed GCD patients was 4.81 years (mean, SD: 6.8 N=209) vs. 4.75 years globally (mean, SD: 6.1 N=1042).

### Diagnostic Tools That Led to Correct Diagnosis Among NET Patients Diagnosed by a GI Specialist:

- The diagnostic tools that most often led to correct diagnosis for SI NET were biopsy (58%, 133/228), CT scan and colonoscopy (both at 38%, 87/228), 5-HIAA in urine and Chromogranin A (CgA) both at 30% (69/228).
- PNETs were diagnosed most often by biopsy (67% 64/95), CT scan (47%, 45/95), MRI (35%, 33/95) and endoscopy (28%, 27/95).
- Rectal NETs were diagnosed in 75% of GCD patients via biopsy (30/40).
- NET diagnoses were received most frequently in hospitals without a NET specialist (GCD 38%, 182/480; Global 41%, 967/2359).

**Figure 3: Correct Diagnostic Tools by NET Primary Site Administered for the GCD Patients**




*** Small sample units, observations only*

## CONCLUSIONS

- The route to correct NET diagnosis is lengthy, with 5 years of misdiagnosis on average, and detection is often incidental or after many wrong guesses.
- Gastroenterologists play a fundamental role in diagnosing NETs.
- Better knowledge of NET symptoms and appropriate diagnostic tools are instrumental in improving the time to NET diagnosis and ensuring optimal patient outcomes.

## ACKNOWLEDGEMENTS

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## REFERENCES

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

## CONTACT INFORMATION

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## POSTER CATEGORY

Neuroendocrine Tumors