

# Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor (NET) Patients (SCAN) – Assessment of Early Diagnosis

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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 incidence of NETs may be increasing due to earlier and improved diagnosis<sup>1,2</sup>
- However, limited understanding of the disease and financial constraints means current availability of diagnostic and treatment tools for NET patients vary considerably within and across healthcare systems, with many patients experiencing suboptimal care<sup>3</sup>

## OBJECTIVES

- This survey (SCAN) aims to measure the global readiness to provide access to diagnostics and treatments for NET patients in terms of:



- This analysis focused on challenges in NET diagnostics

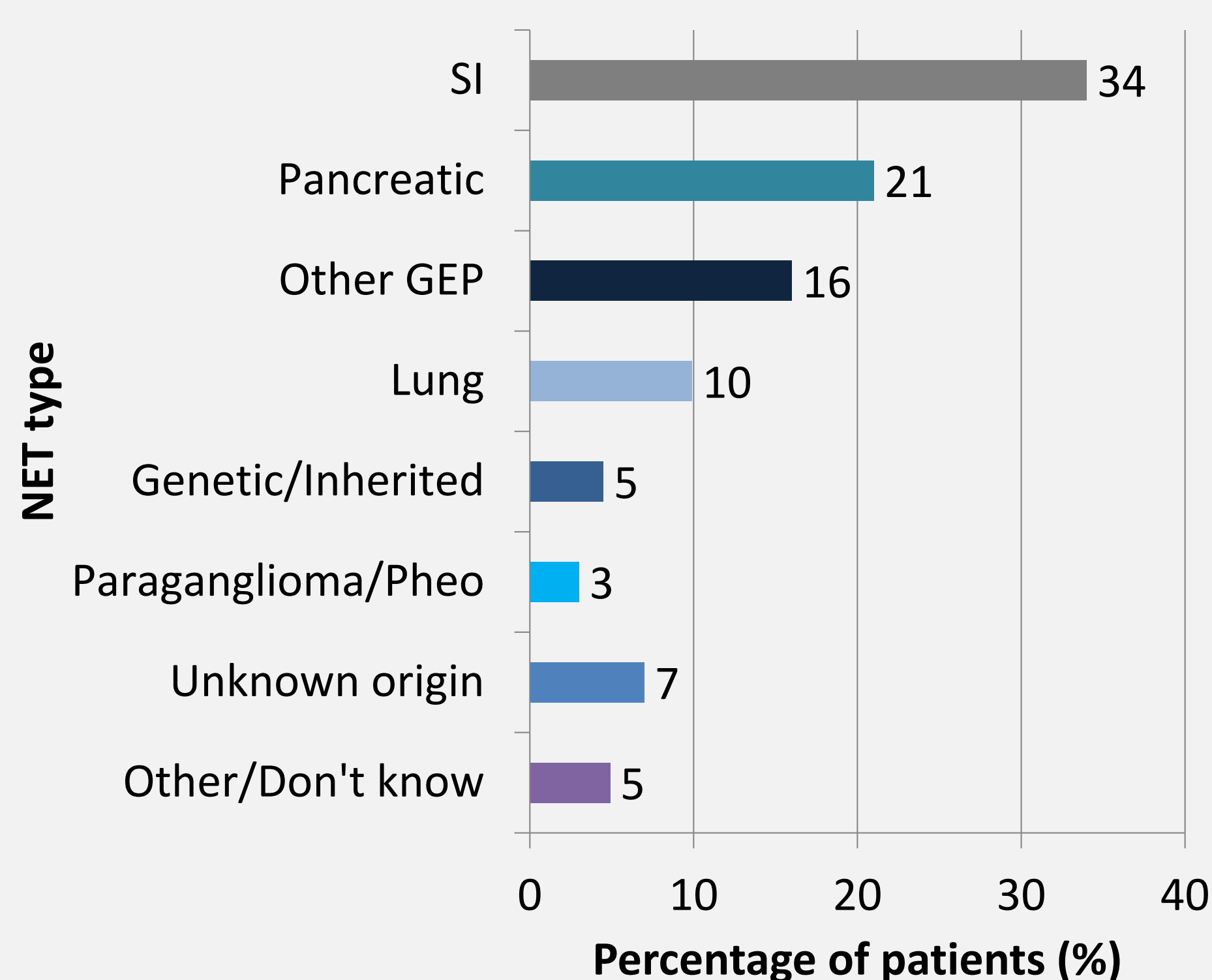
## METHODS

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

## PARTICIPANT CHARACTERISTICS

- There were 2795 respondents from 68 countries across 6 continents: 2359 patients/carers and 436 HCPs
- Most HCPs were medical oncologists (25% [108/436]) or gastrointestinal specialists (15% [66/436])
- Primary NETs were most often gastroenteropancreatic NETs (GEP NET; 71% [1670/2359]) (Figure 1)
  - Particularly, small intestinal (SI: 34% [798/2359]) or pancreatic (21% [488/2359])

Figure 1: NET type by primary site in patient participants

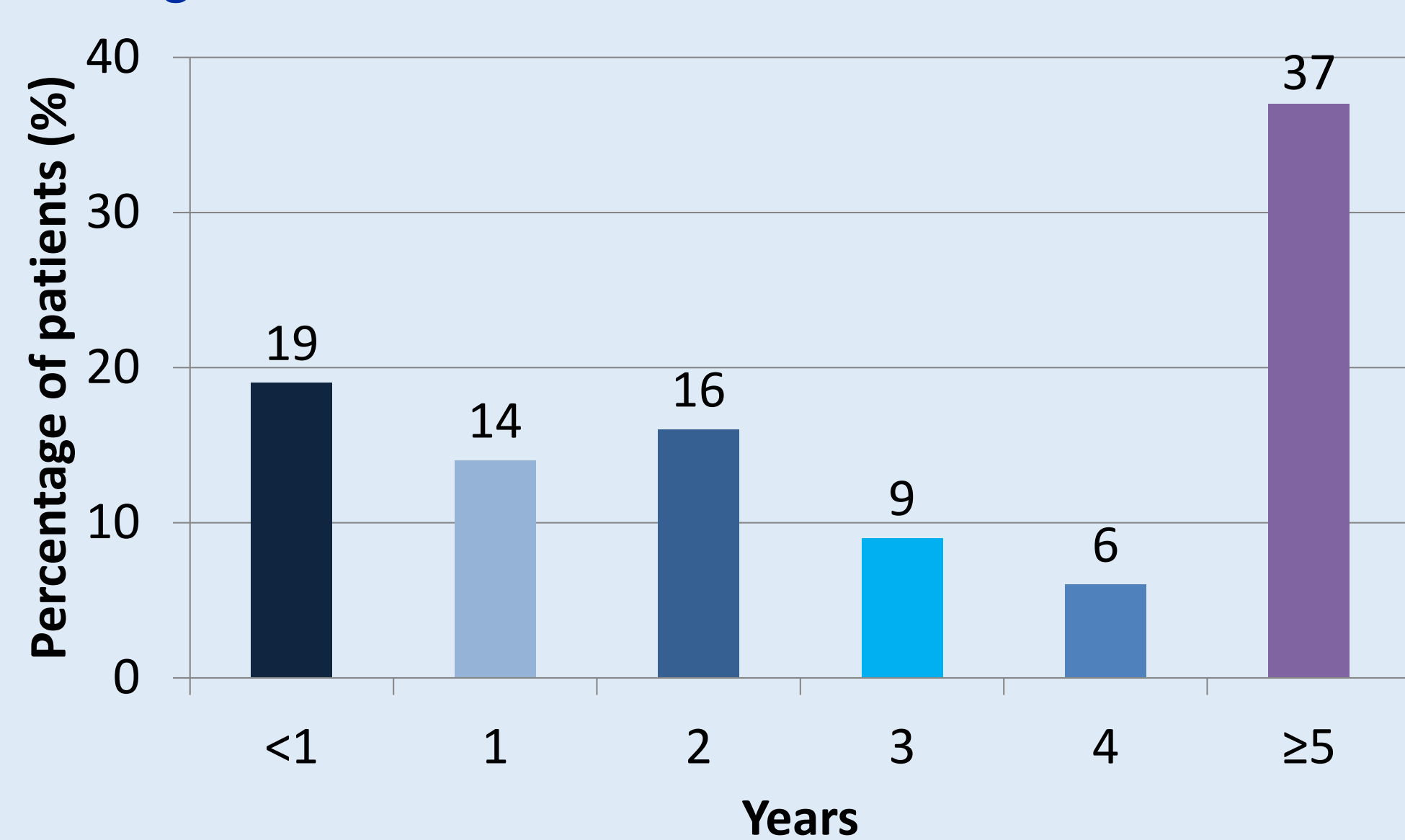


- Mean patient age at the time of diagnosis was 51 years
- Patients had a NET diagnosis for a mean of 5 years

## RESULTS

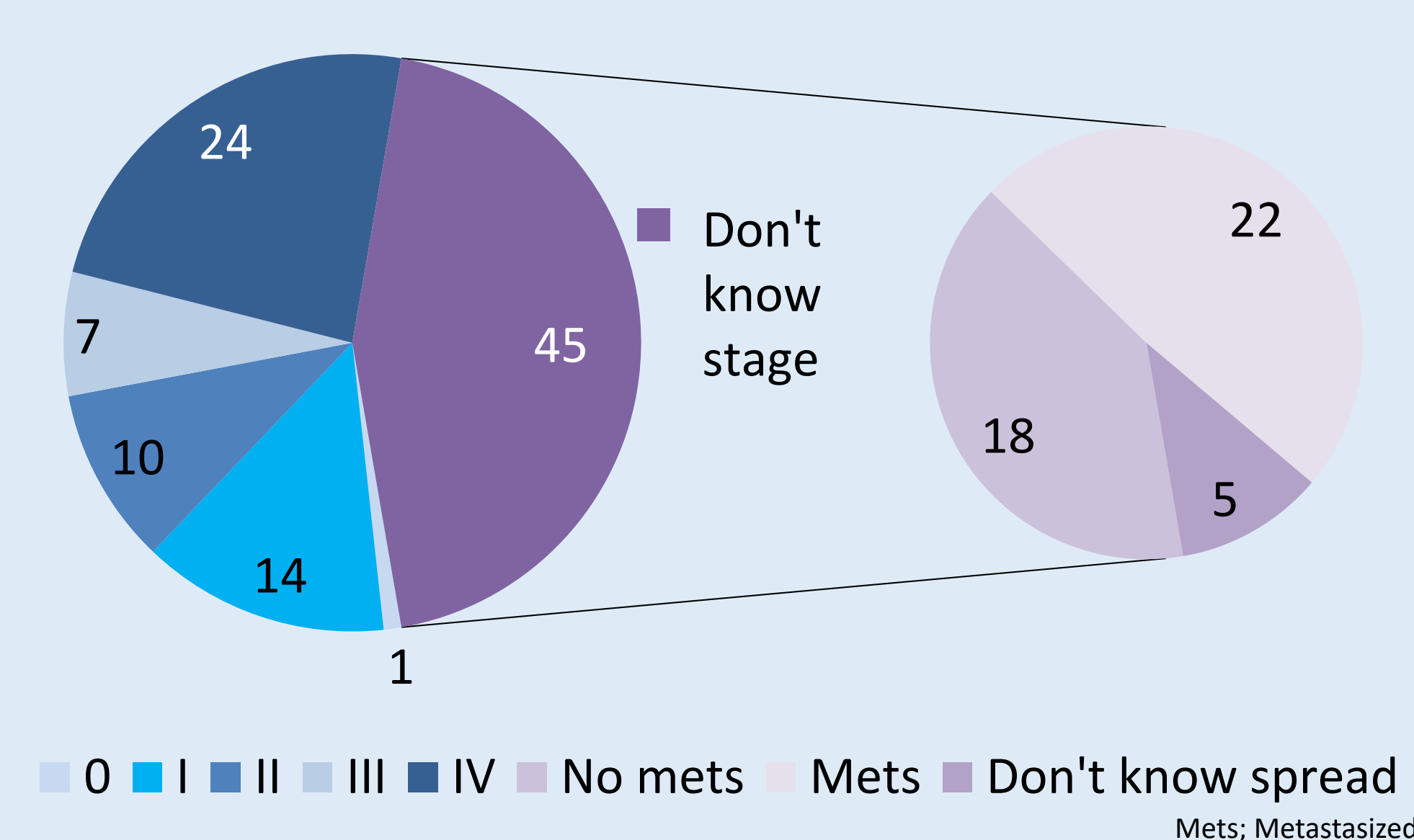
- Almost half of patients were initially misdiagnosed (44% [1043/2359])
  - 27% (640/2359) received a NET diagnosis first time; 26% (606/2359) diagnosed incidentally
- Incorrect diagnoses prior to NET diagnosis included: gastritis (SI: 40% [125/315]; P: 8% [43/159]); irritable bowel syndrome (SI: 48% [150/315]; P: 33% [52/159]); and asthma (Lung: 5% [52/82])
- Mean time to NET diagnosis for misdiagnosed patients was 5 years
- Four out of five misdiagnosed patients (81% [847/1042]) failed to receive a diagnosis within 1 year (Figure 2)

Figure 2: Years between first symptom and diagnosis for those misdiagnosed



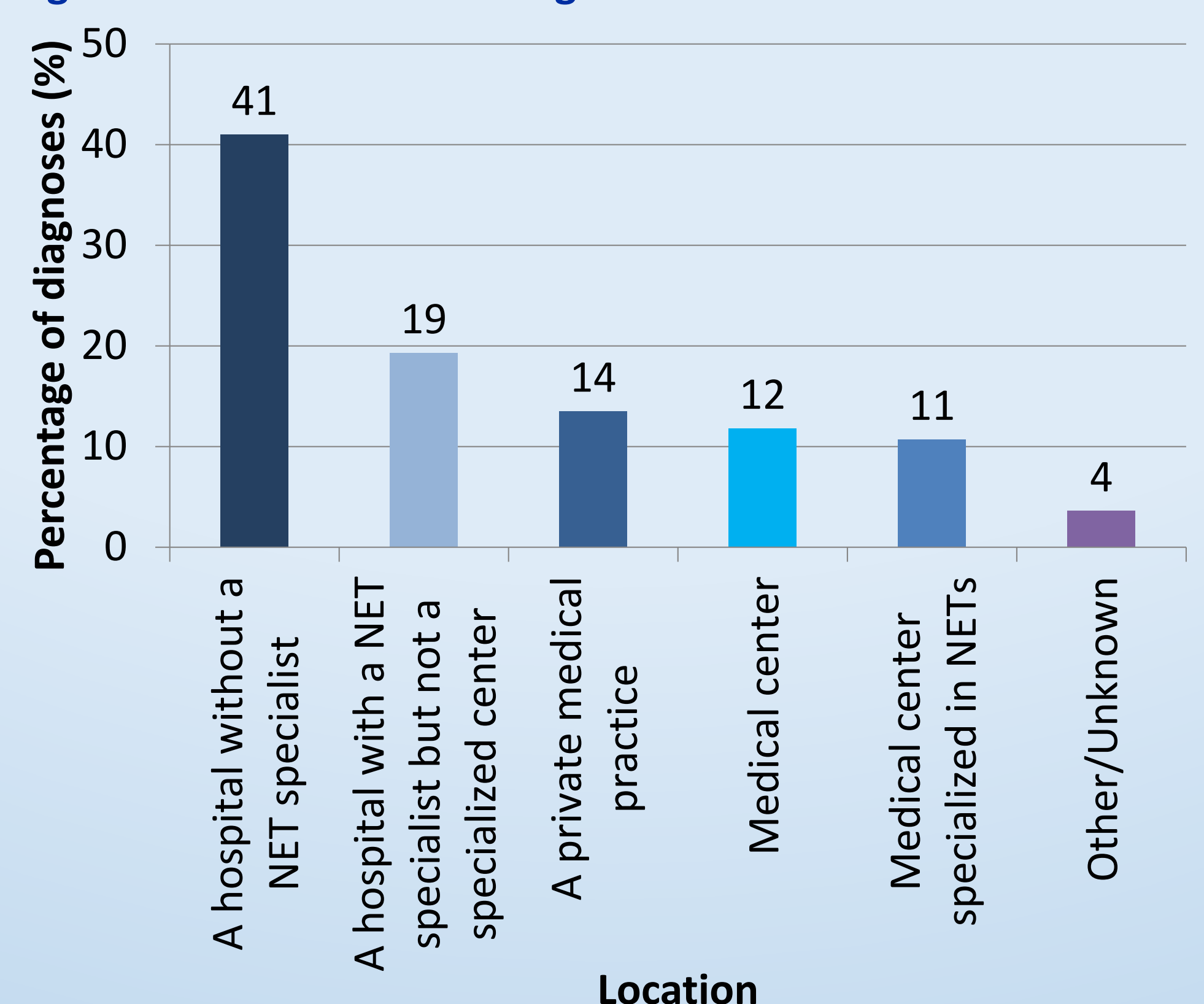
- Almost half of patients (46% [1077/2359]) were diagnosed with stage IV NETs or had metastases at time of diagnosis (Figure 3)
- NETs were: grade 1 (39% [922/2359]); grade 2 (23% [544/2359]); grade 3 (5% [115/2359]); poorly differentiated (4% [101/2359]); unknown (29% [677/2359])

Figure 3: Stage of NET at the time of diagnosis



- Diagnosis occasionally occurred in NET specialist centers (11% [253/2359]) or hospitals with NET experts (19% [456/2359]), but more frequently in hospitals without NET experts (41% [968/2359]) (Figure 4)

Figure 4: Location of NET diagnosis

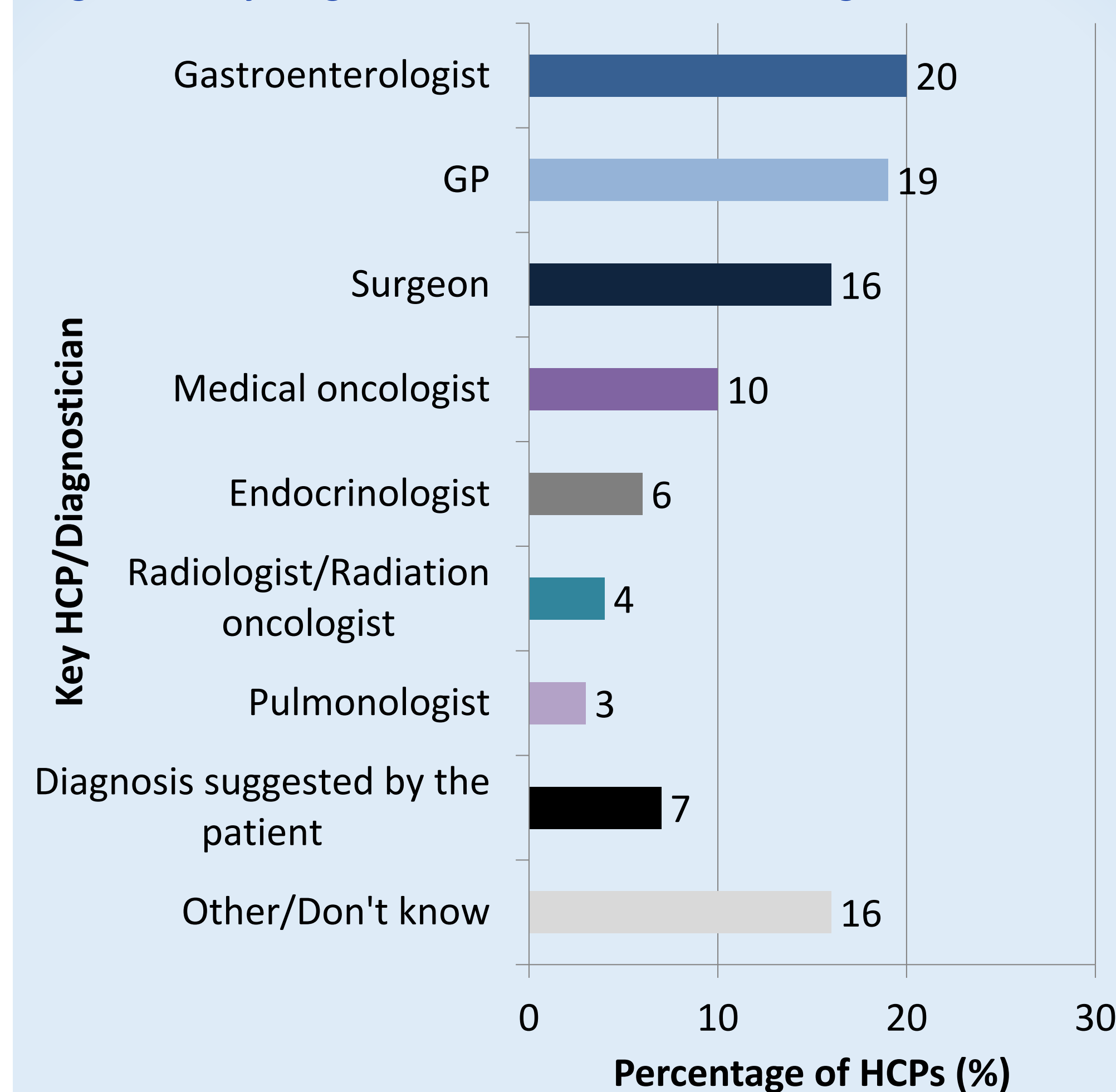


- A quarter (24% [570/2359]) of patients had not heard of NET specialists

## RESULTS continued

- Biopsy (59% [1380/2359]) and CT (45% [1060/2359]) most commonly led to NET diagnosis
- The HCPs most often involved in NET diagnosis were gastroenterologists (20% [480/2359]) and GPs (19% [456/2359]) (Figure 5)

Figure 5: Key diagnostician involved in NET diagnosis



- Two key recommendations to improve NET diagnosis and management were:
  - More HCPs knowledgeable in NETs (Patients: 62% [1470/2359]; HCPs: 50% [217/436])
  - Better access to NET experts/specialist centers (Patients: 53% [1244/2359]; HCPs: 63% [275/436])

## CONCLUSION

- SCAN represents the biggest global compendium of data about NETs extant
- Delayed NET diagnosis remains a global challenge
- Awareness and access to NET specialists and expert centers requires improvement
- SCAN results will help drive forward optimal care and referral pathways to achieve the goal of earlier diagnosis
- Improvements in the usage of more advanced diagnostic tools is needed
- More HCPs knowledgeable in NETs are required with raising awareness among GPs to be a focus of common efforts
- This survey further contributes to positioning NET research on an equal footing with other cancers of similar prevalence

## REFERENCES

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The authors have nothing to declare.