



DIAGNOSING COLORECTAL NETS – SURVEY OF CHALLENGES IN ACCESS TO DIAGNOSTICS AND TREATMENT FOR NEUROENDOCRINE TUMOR (NET) PATIENTS (SCAN)

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INTRODUCTION

- Neuroendocrine tumors (NETs) are rare and complex neoplasms with increasing incidence and prevalence worldwide.¹

OBJECTIVE

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



- This analysis focused on early diagnosis of NET patients with colonic and rectal primary NET.

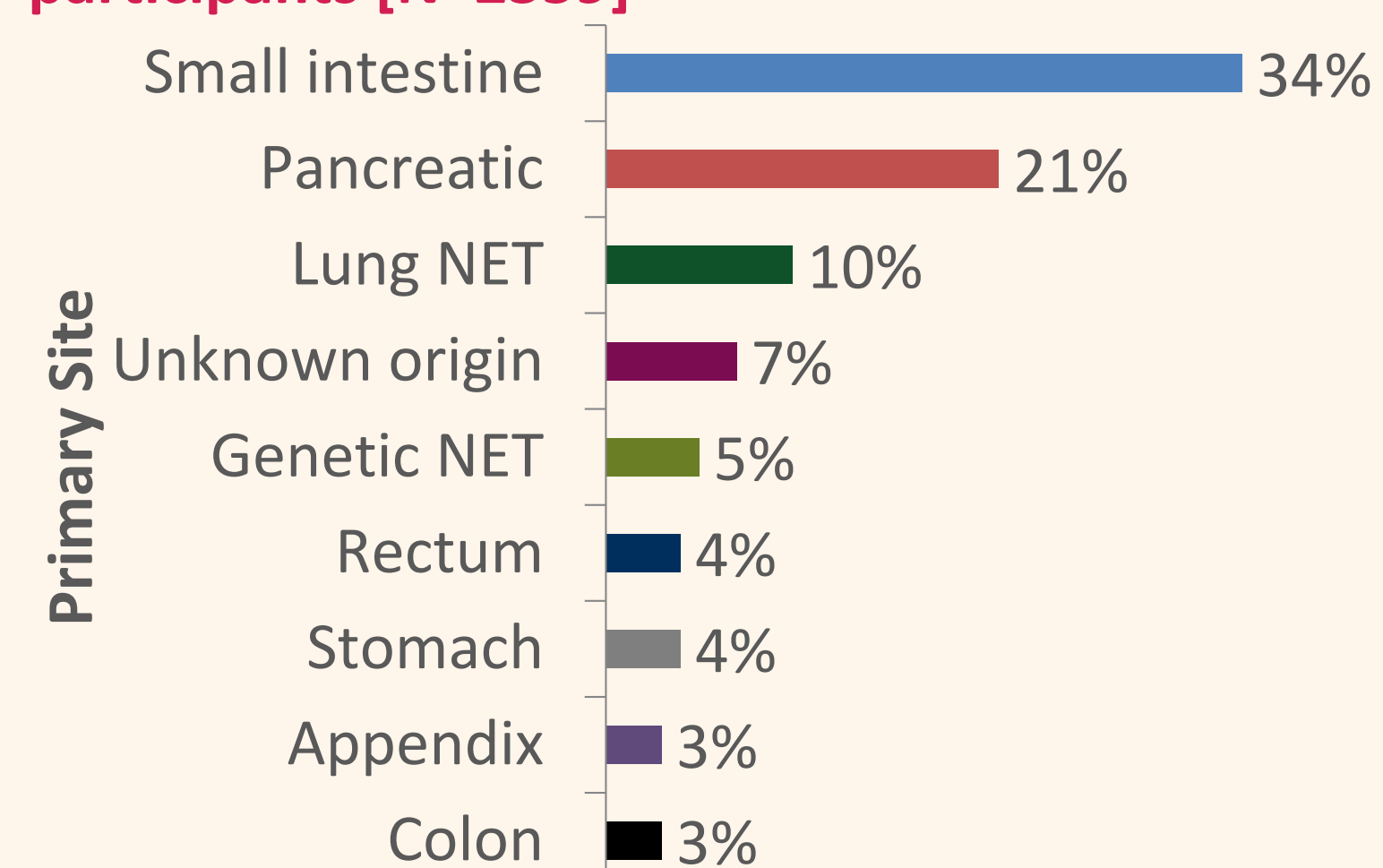
METHODS

- During Sept-Nov 2019, NET patients and healthcare professionals (HCP) 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.

PARTICIPANT CHARACTERISTICS

- 2359 NET patients and 436 HCPs from 68 countries responded
- 7% [153/2359] were diagnosed with primary NET of the colon [39% (59/153)] and the rectum [61% (94/153)] (Figure 1).
- Average colorectal NET patient age at the time of diagnosis was 51 years with an average of 4 years living with the disease.

Figure 1: NET type by primary site in NET patient participants [N=2359]

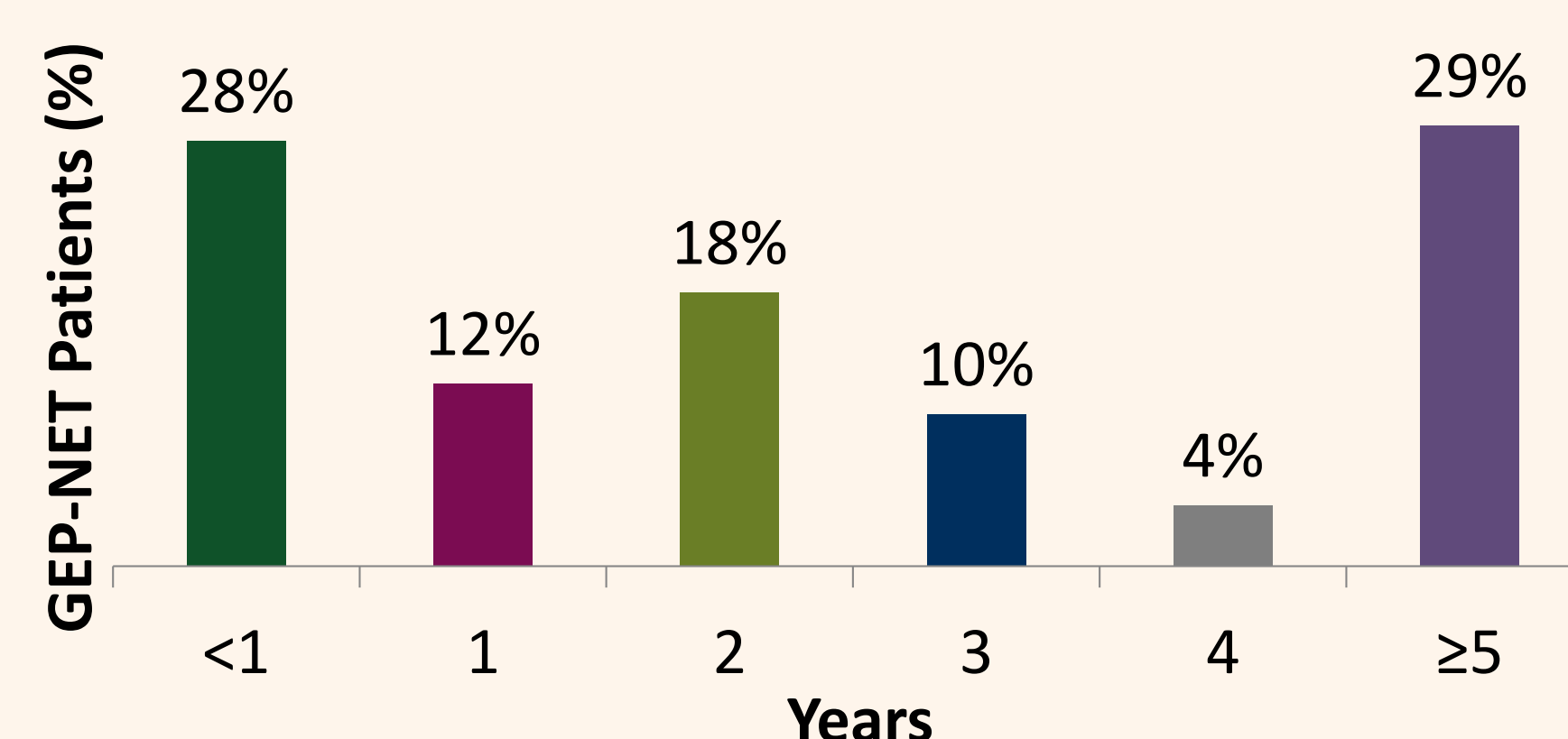


RESULTS

NET Staging and Misdiagnosing

- Every third colorectal NET patient had stage IV NET at diagnosis (32% [49/153]), colonic NET patients diagnosed with stage IV were 51% (30/58), rectal NET patients diagnosed with stage IV were 20% (19/97).
- Slightly above a third reported they were misdiagnosed at least once with another condition prior to receiving the correct diagnosis (34% [52/153])

Figure 2: Years between first symptom and diagnosis for those initially misdiagnosed [N=52]

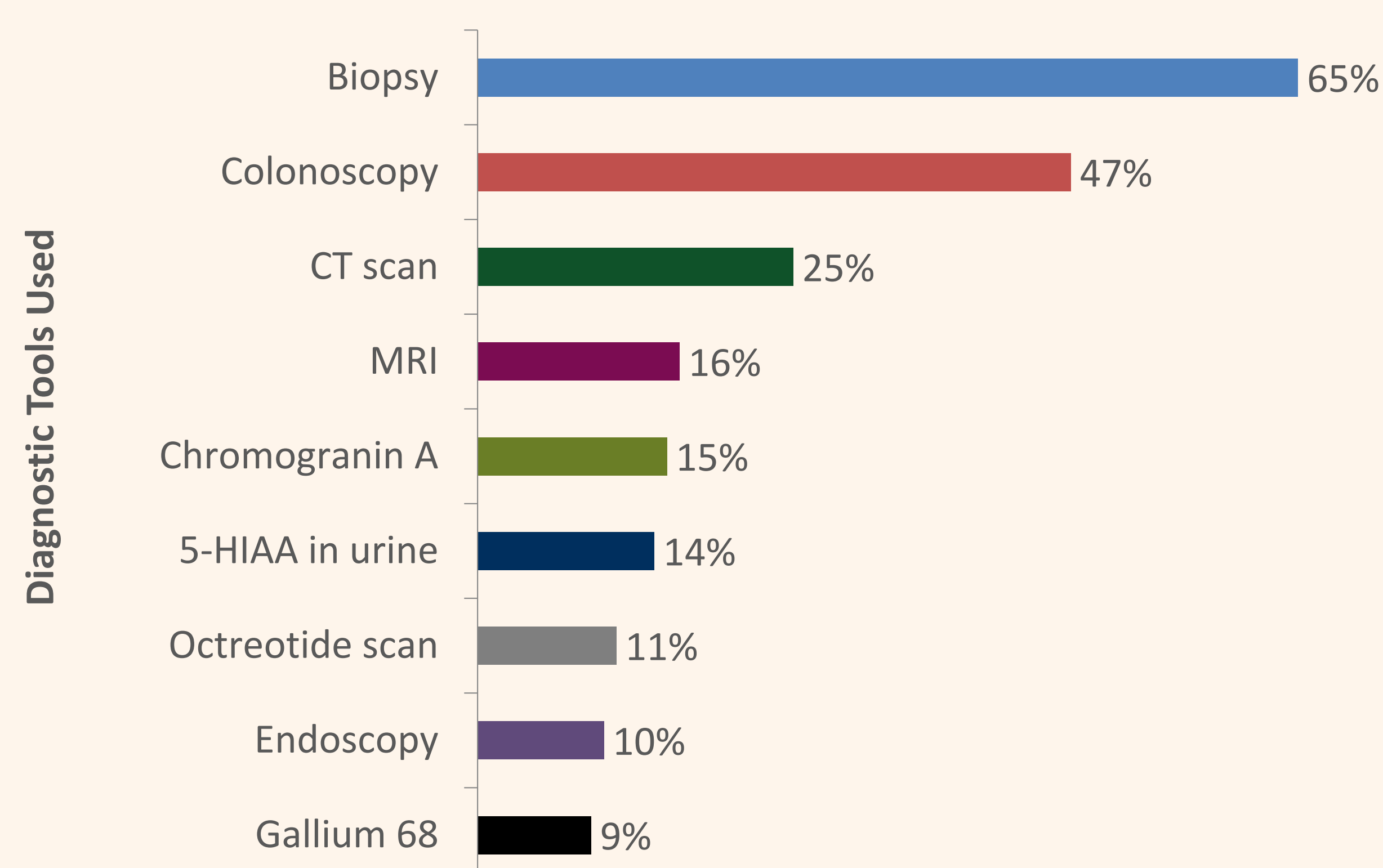


- Mean time to correct diagnosis for the misdiagnosed was 4.16 years (N=52). A third were misdiagnosed for more than 5 years (Figure 2).
- The most common misdiagnosed conditions were gastritis (54% (28/52)) and Irritable Bowel Syndrome (IBS) (50% (26/52)).
- NET was discovered incidentally while testing for another condition in another third of the cases (31% [48/153]).
- Only in 31% of patients, colorectal NET was the first diagnosis received after initial symptoms.

Diagnostics

- The diagnostic tools that most often led to the correct diagnosis were biopsy (65% [98/153]) and colonoscopy (47% [71/153]). (Figure 3).

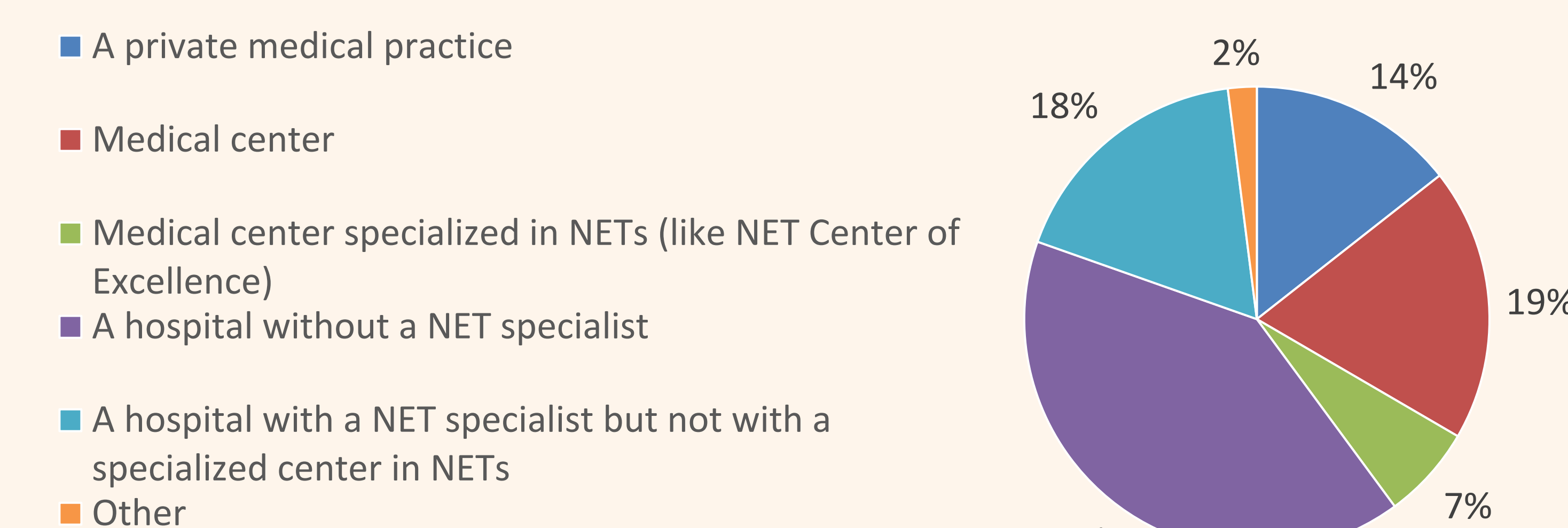
Figure 3: Diagnostic tools that lead to correct colorectal NET diagnosis [N=153]



HCP involvement

- The clinicians who most commonly suggested the test were gastroenterologists [34% (54/153)] or surgeons [20% (30/153)].
- The majority of colorectal NET patients received their diagnosis at a hospital without a NET specialist (41% [62/153]) (Figure 4).

Figure 4: Place where diagnosis was received [N=153]



RESULTS [cont.]

Issues and recommendations

- The most frequent issues reported by colorectal NET patients were 'Lack of experts to provide first or second opinion on their case' (22% [23/105]) and 'Lack of access to reliable information about their NET' (19% [20/105]).
- Most common recommendations made by colorectal NET patients with regards to improving NET care were 'better access to NET experts/specialist centres' (66% [101/153]) and 'more HCPs knowledgeable in NETs' (60% [91/153]).

CONCLUSION

- SCAN represents the biggest global compendium of data about NETs extant
- Misdiagnosis and incidental diagnosis lead to an extremely high proportion of NET patients diagnosed with stage IV, associated with poorer patient outcomes and remains a global challenge.
- Key requirements to further drive forward improvements in global NETs care include:
 - More knowledge about NETs among colorectal medical specialists is vital for early detection and timely referral for proper testing

REFERENCES

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

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