

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

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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 and availability of diagnostic and treatment tools in gastroenteropancreatic (GEP) NET patients.

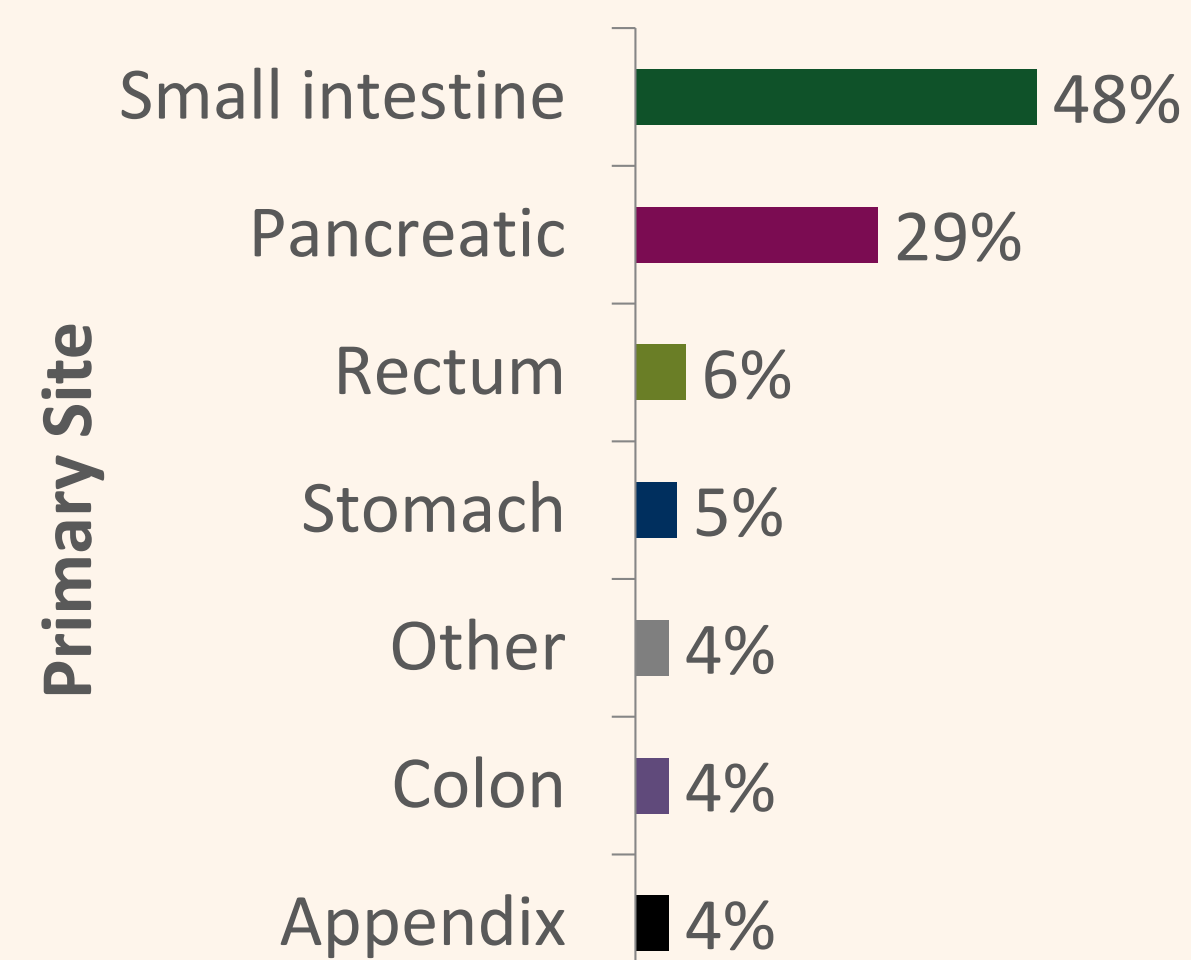
METHODS

- 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

- There were 1670 GEP-NET patients (female 61% [1012/1670]) from 53 countries across 6 continents.
- Average age was 57 (SD 12) years and patients had a NET diagnosis for a mean of 5 (SD 5) years.
- GEP-NETs were most commonly small intestinal (48% [798/1670]) and pancreatic (29% [488/1670]) (Figure 1).

Figure 1: NET type by primary site in GEP-NET patient participants [N=1670]

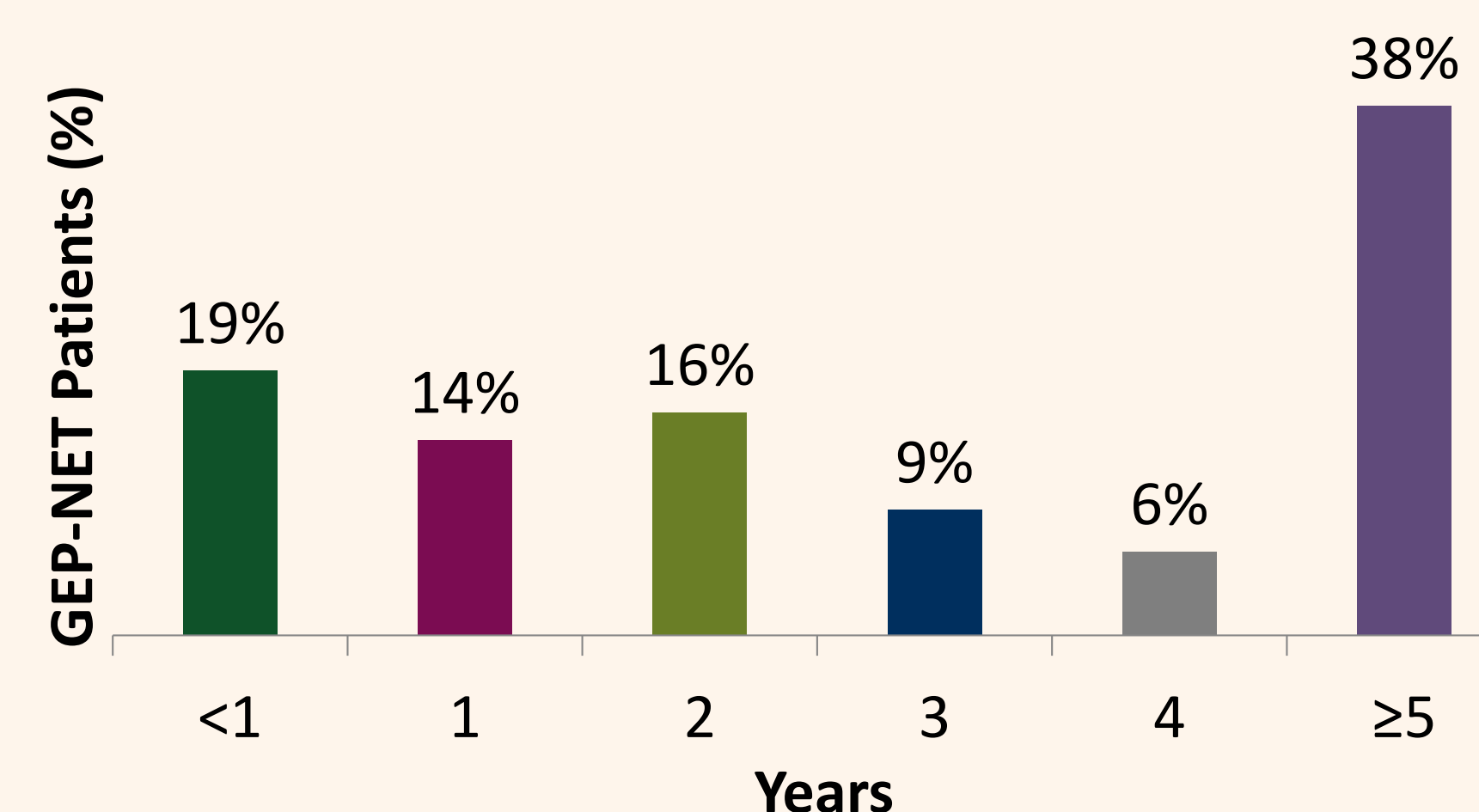


RESULTS

Misdiagnosis

- Almost half of GEP-NET patients were initially misdiagnosed (44% [727/1670]).
- The top 3 misdiagnoses were gastritis (44% [254/582]), irritable bowel syndrome (44% [254/582]) and anxiety (23% [131/582]).
- Only 18% (134/726) of misdiagnosed patients were diagnosed within 1 year and mean time to diagnosis was 5 (SD 6) years (Figure 2).

Figure 2: Years between first symptom and diagnosis for those initially misdiagnosed [N=726]



- More than one-third of GEP-NET patients (38% [638/1670]) were diagnosed with stage IV NETs or metastases at time of diagnosis.
- At diagnosis, 43% (712/1670) of NETs were grade 1, 26% grade 2 (438/1670), 4% grade 3 (74/1670), 3% (52/1670) poorly differentiated, and 24% (394/1670) unknown.

Diagnostics and treatment availability

- Biopsy was the most widely available diagnostic option (80% [1332/1670]), followed by CT (77% [1293/1670]). Over a third reported specialized diagnostics, such as ⁶⁸Ga-DOTA PET CT (39% [657/1670]) and Chromogranin A (CgA: 39% [654/1670]) as unavailable (Figure 3).
- Surgery was a widely available treatment option (81% [1350/1670]). Almost half (45% [746/1670]) stated peptide receptor radionuclide therapy (PRRT) was not available. Somatostatin analogues were available to over two-thirds (68% [1131/1670]) (Figure 4).

Figure 3: Availability of Diagnostic Tools [N=1670]

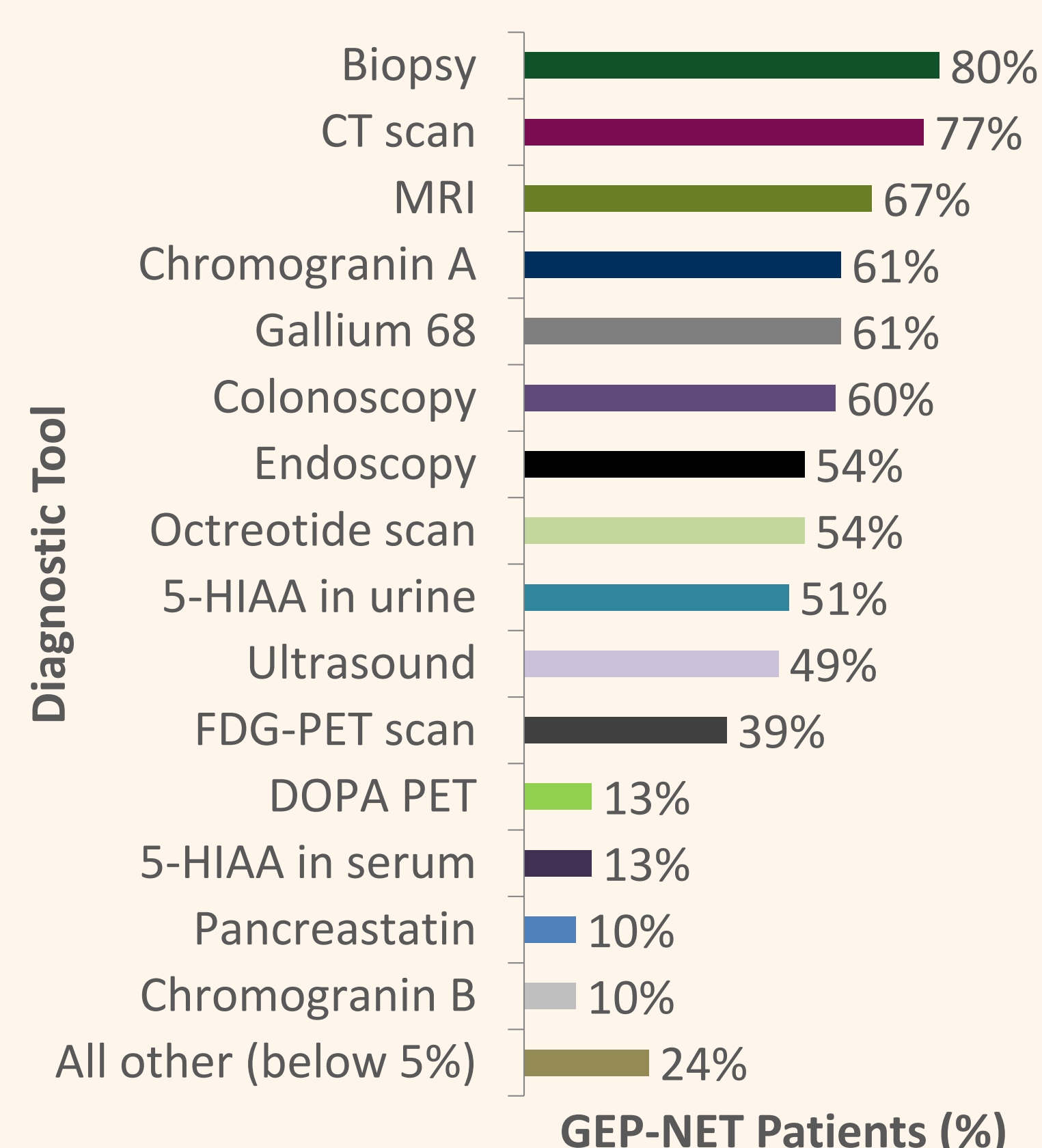
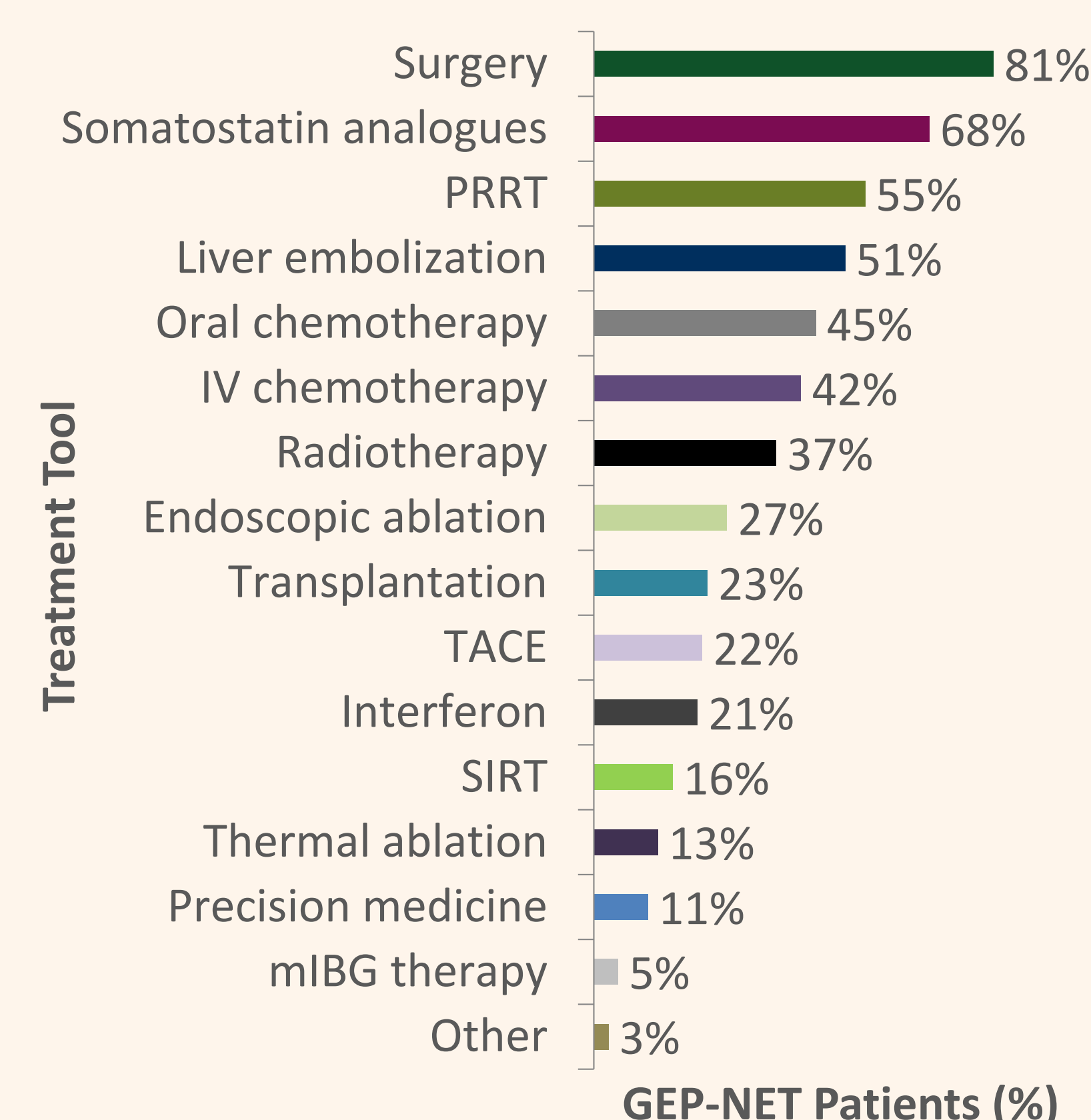


Figure 4: Availability of Treatment Tools [N=1670]



- Conventional imaging, such as CT/MRI/ultrasound, was commonly available (82% [1374/1670]) for ongoing monitoring. Approximately a third believed ongoing monitoring with CgA (35% [578/1670]) or ⁶⁸Ga-DOTA PET CT (38% [633/1670]) was unavailable.

HCP involvement

- Commonly, GEP-NET patients had more than one HCP involved in their diagnosis: 11% one HCP (190/1670), 40% two HCPs (672/1670), 22% three HCPs (372/1670), 24% four or more HCPs (398/1670) and 2% (38/1670) could not say.
- Leading diagnosticians were gastroenterologists (26% [435/1670]) and GPs (20% [334/1670]).

RESULTS [cont.]

Issues and recommendations

- Of those GEP-NET patients reporting issues, the most frequent were a 'lack of access to reliable information about your NET' (37% [384/1036]) and 'lack of experts to provide first or second opinion on your case' (32% [332/1036]).
- Of those GEP-NET patients providing recommendations to improve NET care, the most common were 'more HCPs knowledgeable in NETs' (68% [1063/1571]) and 'better access to NET experts/specialist centres' (54% [844/1571]).

CONCLUSION

- SCAN represents the biggest global compendium of data about NETs extant
- Delayed GEP-NET diagnosis remains a significant challenge and more reliable information on GEP-NETs is needed.
- Key requirements to further drive forward improvements in global NETs care include:
 - Increasing the availability of NET diagnostics and treatment, particularly newer, more specialized tools
 - Increasing the number of knowledgeable HCPs, especially gastroenterologists and GPs

REFERENCES

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

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