

A Collaboration Between the International Neuroendocrine Cancer Alliance (INCA) and Novartis

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BACKGROUND

- Diagnosis of NETs often occurs late in the disease course¹
 - Symptoms are nonspecific, and some patients remain asymptomatic until metastasis has occurred¹⁻³
 - NET-related symptoms may persist for many years before NETs are diagnosed, by which point metastases have developed in most patients^{1,4}
- Delayed diagnosis can substantially worsen prognosis
 - Localized disease is associated with substantially better outcomes than advanced disease with distant metastases⁵
- Although NET awareness and diagnostic techniques have improved, diagnosis remains challenging, and the NET patient experience has not been well examined
- INCA is a network of 18 independent charitable organizations and patient groups from 15 countries around the world. Novartis Pharmaceuticals Corporation collaborated with INCA on the first global survey to gather data about the NET patient experience from multiple countries, with the goals of
 - Capturing individual patient experiences of a NET diagnosis to increase understanding of the NET journey and the needs of patients with NETs
 - Highlighting differences and similarities between countries and regions to help improve NET awareness and care
- We present European (EU) patient-reported data on time to diagnosis in NETs

OBJECTIVE

- To raise awareness of the NET patient perspective, including challenges faced while seeking a diagnosis

METHODS

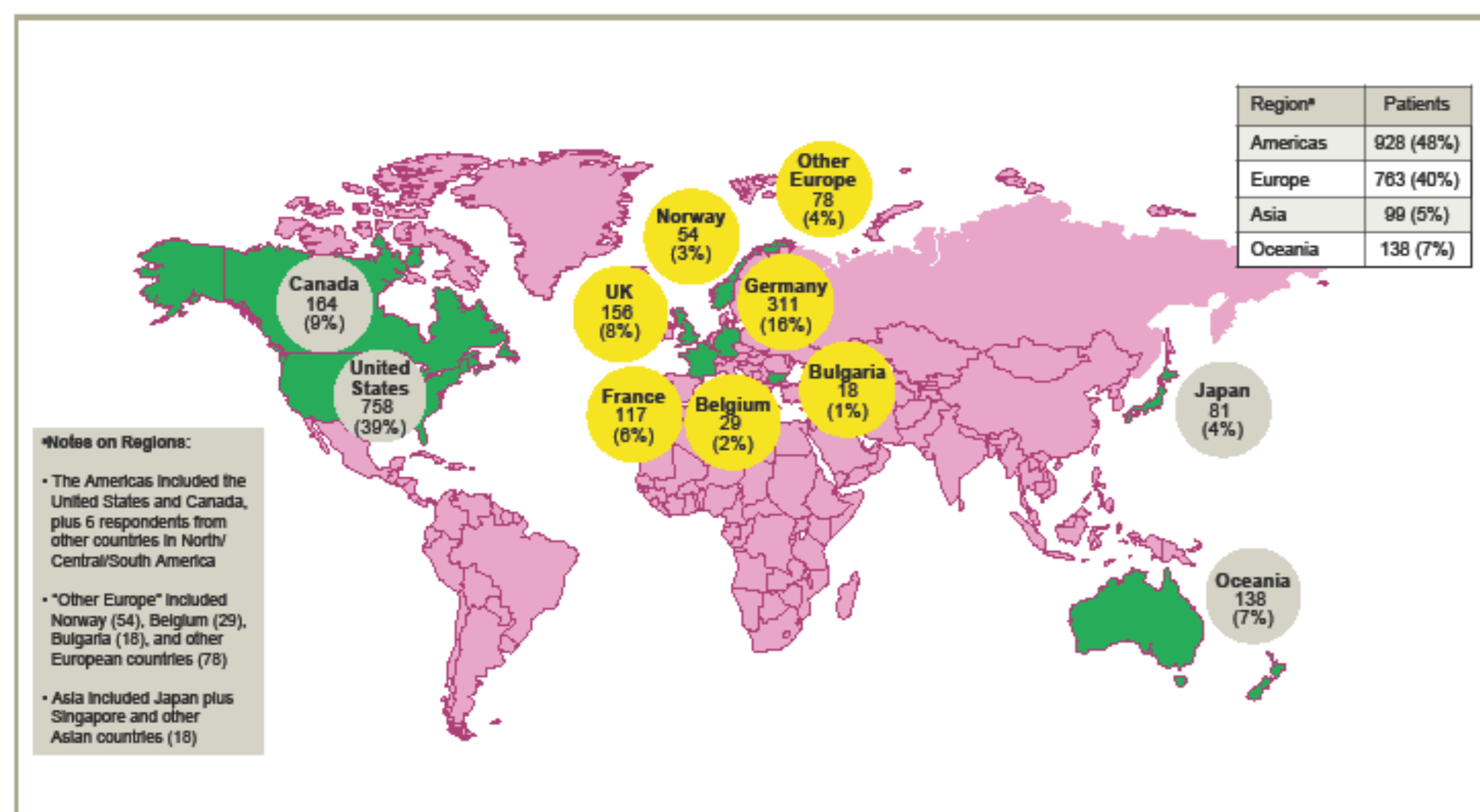
- From February through May 2014, patients with NETs participated in a 25-minute anonymous survey that captured the NET patient experience, including their diagnostic journey
 - With the exception of certain demographic information, survey questions were closed-ended; participants were provided options from which to choose
- Patients were recruited via use of flyers, Web site postings, e-mails, and social media channels of the INCA member organizations/patient advocacy groups (in 2014, INCA consisted of 17 organizations in 14 countries)
 - Extensive use of online social media through local/regional advocacy groups allowed recruitment of a large number of patients with this rare type of cancer
- Primarily conducted online and available in 8 languages: Bulgarian, Dutch, English, French, German, Japanese, Norwegian, and simplified Chinese
 - Paper surveys were developed in several languages and distributed by patient groups and health care providers (HCPs) to reach patients without internet
- Data were analyzed at global, regional, and country levels; here we present results from the EU data
 - Statistical differences between comparisons were significant at the 95% confidence level ($P < .05$) for all statements within the text; statistically significant differences within figures are indicated by **blue text**
 - For the figures shown, base population $n = 763$, unless otherwise specified
- This survey was conducted as an equal collaboration between INCA and Novartis, and was funded by Novartis. Hall & Partners, a research organization, fielded and analyzed the results

RESULTS

Demographics

- A total of 1928 patients with NETs were recruited from >12 countries in the Americas, Asia, EU, and Oceania (Figure 1)
- The majority of respondents were from EU ($n = 763$) and North America ($n = 922$)

Figure 1. Countries participating in the global NET patient survey.



Base: All respondents ($n = 1928$). Question: In which country do you live? In which region do you live?

- The average age of EU patients was 58 years; 57% were female
- Gastrointestinal (GI) NETs were the most common subtype reported (53%), followed by pancreatic NET (pNET) (27%), lung NET (10%), other (8%), thymus (1%), and unknown site (4%)
- Most patients had grade (G) 1 (41%) or G2 (26%) functional disease (44%) (defined as tumors that produce symptoms caused by the secretion of hormones [eg, flushing, diarrhea, wheezing, cramping])

The Diagnostic Journey

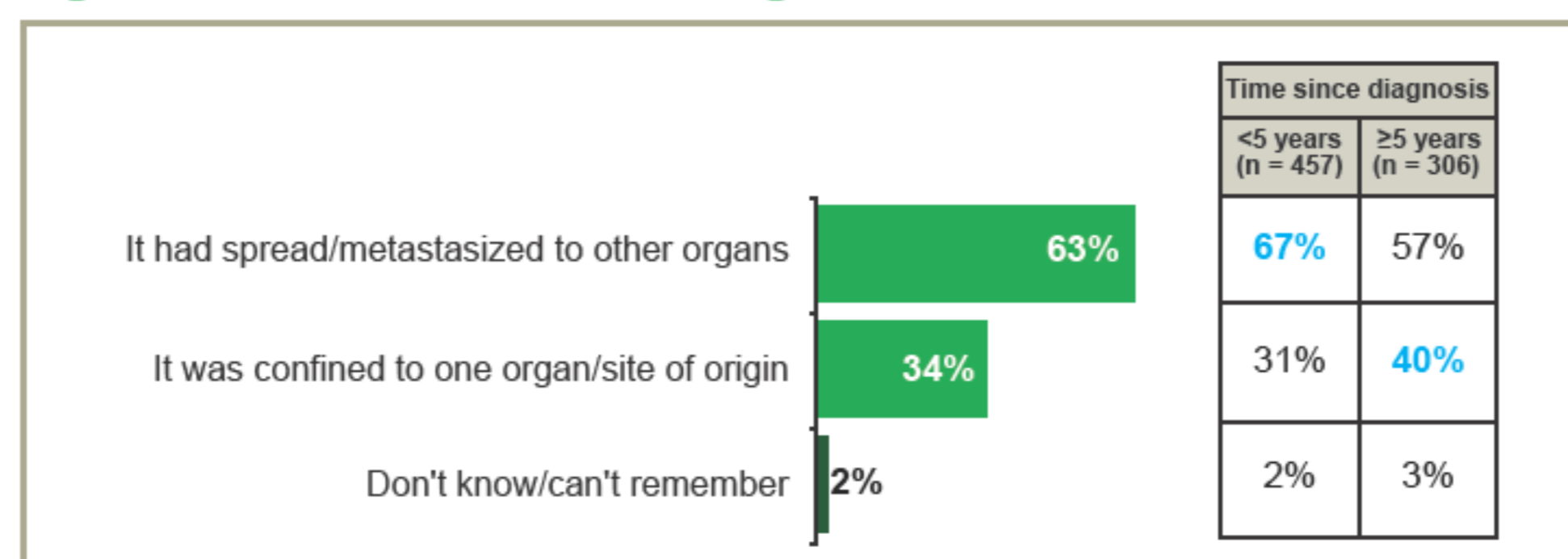
- 60% of respondents reported being diagnosed <5 years ago
- The median time from symptom onset to diagnosis was 24 months
- Time to a diagnosis of NET following the first symptom has improved by approximately 10 months in patients diagnosed more recently (<5 years ago vs ≥5 years ago) (Figure 2)
 - However, 28% of patients still required ≥5 years for a NET diagnosis
- 63% of patients had metastases at diagnosis (Figure 3)
 - The rate was significantly higher in patients diagnosed <5 years (67%) vs ≥5 years ago (57%)

Figure 2. Time between first symptom and a NET diagnosis.



NA, not applicable. Question: What was the approximate length of time between your first symptom and your NET diagnosis? $P < .05$ for patients diagnosed <5 vs ≥5 years ago.

Figure 3. Tumor metastasis at diagnosis.

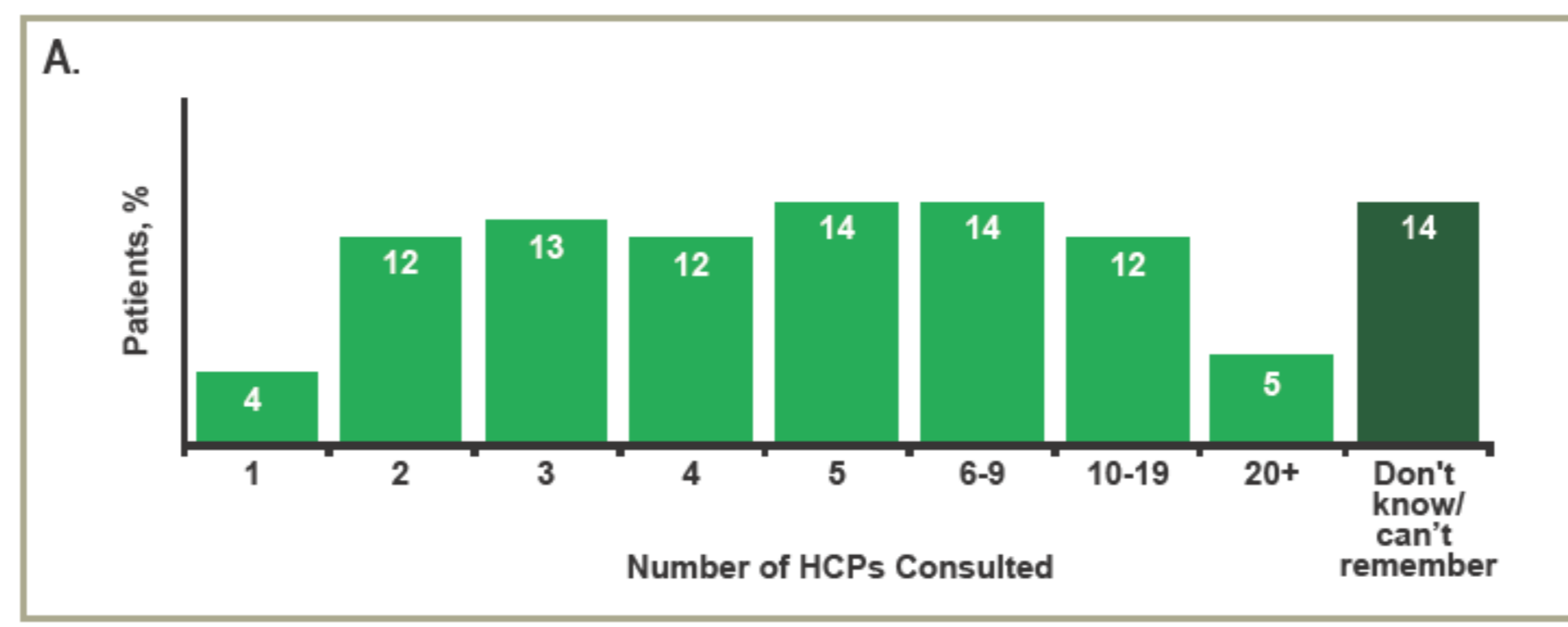


Question: Which of the following best describes your NET at the time of diagnosis? $P < .05$ for patients diagnosed <5 vs ≥5 years ago.

Health Care Resource Use

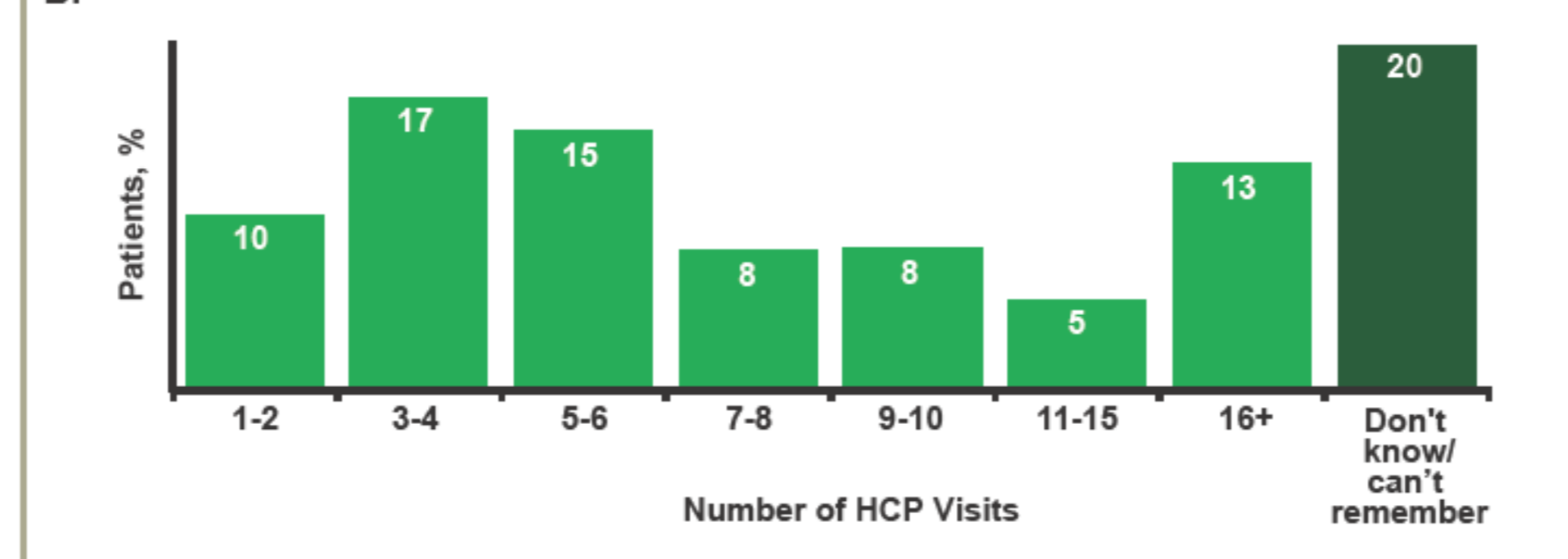
- Patients saw a mean of 7 HCPs with a mean of 11 HCP visits prior to NET diagnosis
 - The number of HCPs consulted and HCP visits made are shown in Figure 4
- 67% of respondents had visited a NET specialty center at least once, but only 25% were diagnosed there (Figure 5)
 - Diagnosis at a NET specialty center was similarly likely to occur in patients diagnosed <5 years (26%) versus ≥5 years ago (25%)

Figure 4. Number of HCPs and HCP visits involved in receiving a NET diagnosis.



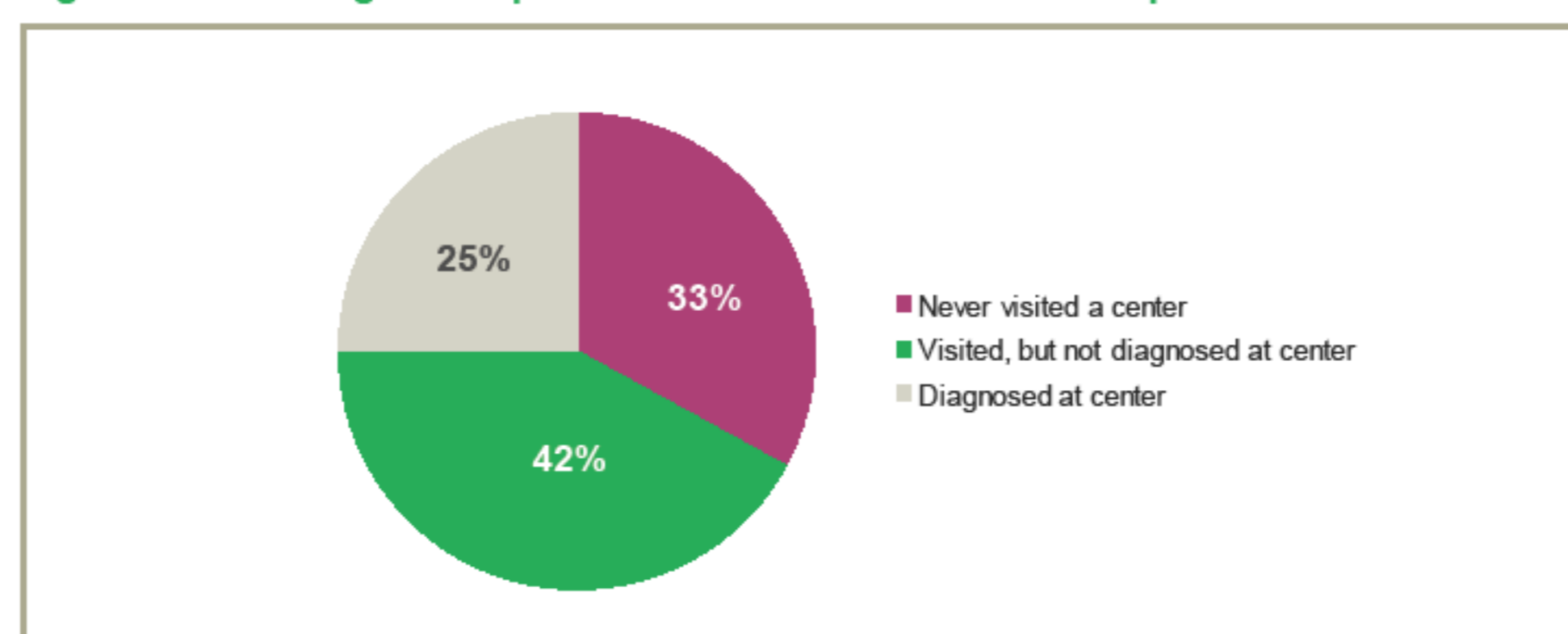
Question: Approximately how many HCPs (including all doctors, specialists, and nurses) were involved in your diagnosis of a NET?

Figure 5. Percentage of respondents who had been to a NET specialist center.



Question: Approximately how many different visits to HCPs (including all doctors, specialists, and nurses) did you have to make?

Figure 6. Experience of getting a NET diagnosis.

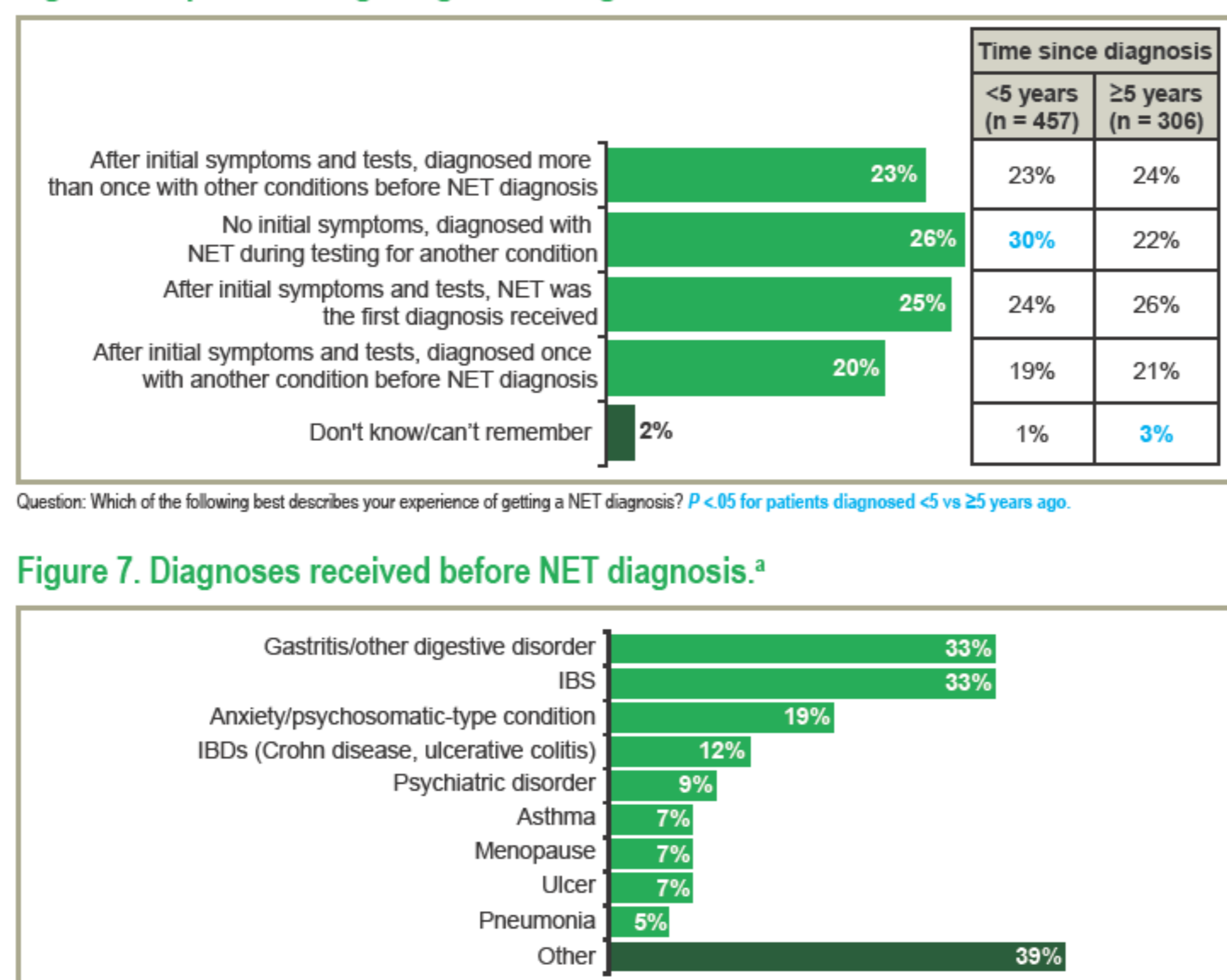


Question: Have you ever been to a medical center that specializes in NET and has a team of different HCPs to help manage your NET? Did you receive your NET diagnosis at a medical center that specializes in NET?

Diagnostic Challenges

- For nearly half of the patients (43%), NET was not the initial diagnosis (Figure 6)
- About one-quarter of patients (26%) reported being diagnosed with NETs during testing for another condition (Figure 6)
 - This occurred significantly more often among more recently diagnosed patients (<5 years ago, 30%) versus those diagnosed ≥5 years ago (22%)
- The most common early diagnoses were digestive disorders such as irritable bowel syndrome (IBS), gastritis or other digestive disorders, and inflammatory bowel diseases (IBDs), including Crohn disease (Figure 7)
 - 28% were diagnosed with anxiety, a psychosomatic condition, or a psychiatric disorder

Figure 7. Diagnoses received before NET diagnosis.^a



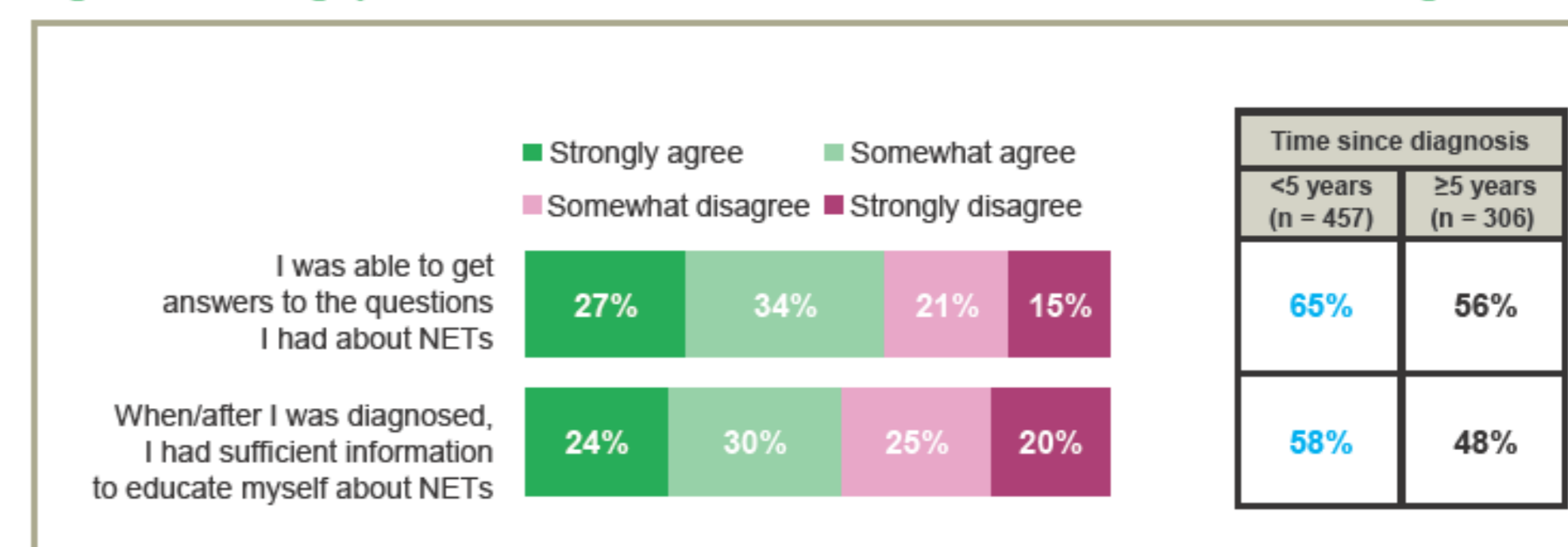
^aIncludes conditions mentioned by ≥2% of patients. Base population: All EU respondents who were diagnosed with other conditions ($n = 330$). Question: Which of the following conditions were you initially diagnosed with prior to receiving a NET diagnosis?

Patient Perspective

- Most patients (74%) did not suspect their symptoms were cancer related
- At the time of diagnosis, many patients got the impression from their physician that NETs were an uncommon form of cancer (67%) in slow motion (59%) that was malignant (38%)
- Upon diagnosis with NETs, patients typically felt shocked (53%), scared (50%), uncertain (49%), and bewildered (36%)
- At the time of diagnosis, only 27% of patients felt strongly that they were able to get answers to their questions about NETs, and 24% strongly agreed that they received sufficient information (Figure 8)
 - The rate for strongly/somewhat agree was significantly higher for those diagnosed <5 years ago than ≥5 years ago

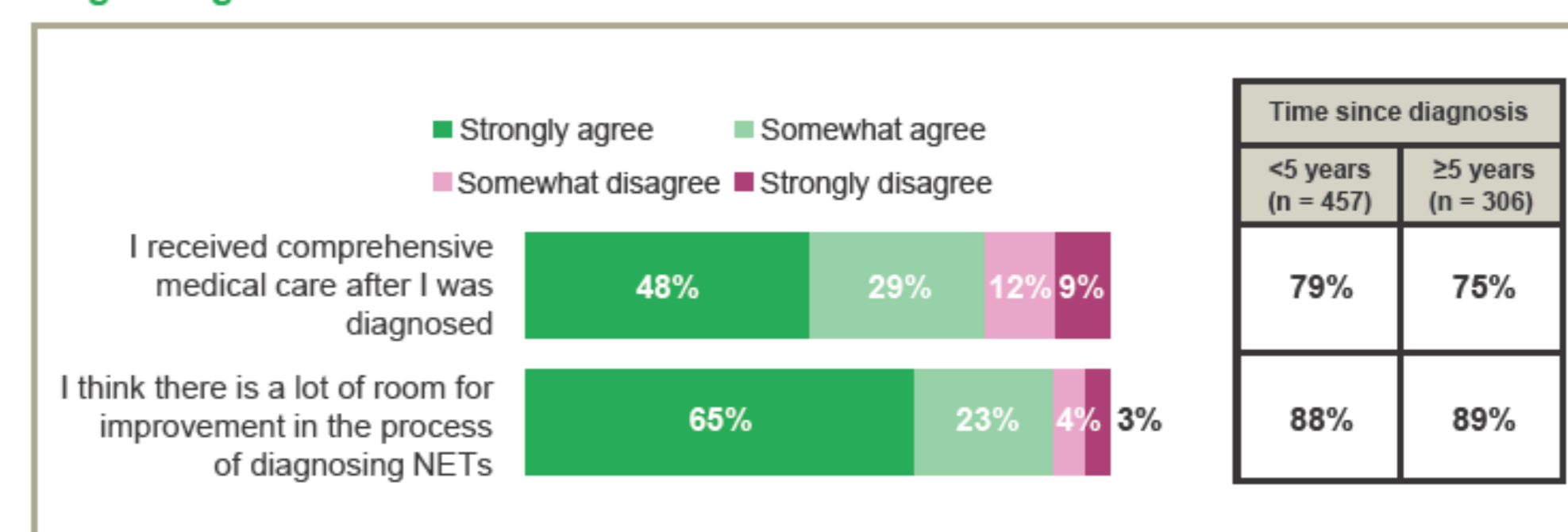
- Although the majority of patients (77%) felt they received comprehensive medical care, 88% still felt there was a lot of room for improvement in NET diagnosis (Figure 9)
 - No significant differences were found between patients diagnosed <5 years versus ≥5 years ago
- Patients felt that many aspects of NET diagnosis could be improved, including receiving clearer information on long-term impact (52%), more immediate access to HCPs with NET expertise (41%), and more knowledgeable HCPs (36%) (Figure 10)

Figure 8. Getting questions answered and sufficient information after NET diagnosis.



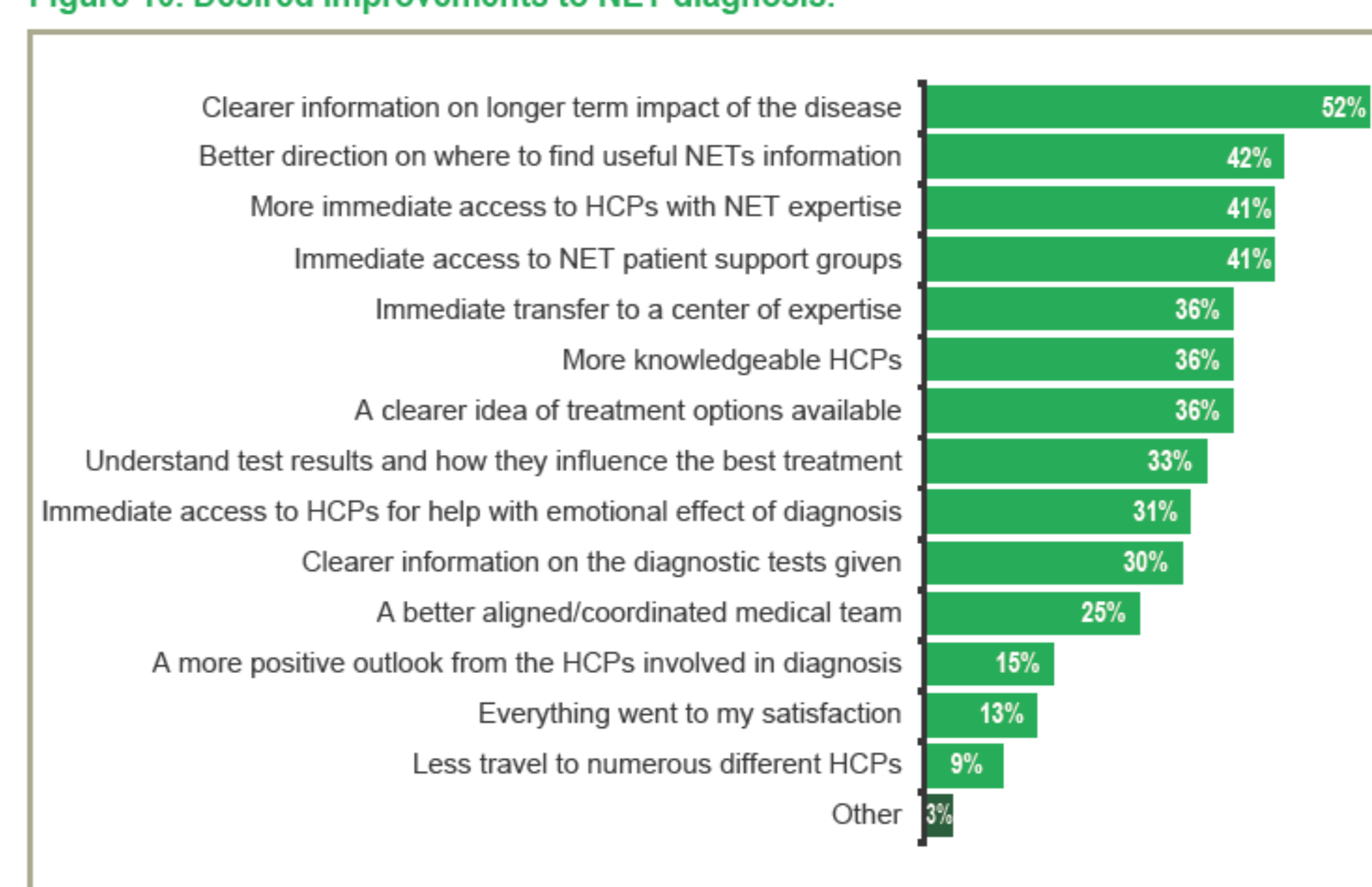
Question: To what extent do you agree or disagree with the following statements? $P < .05$ for patients diagnosed <5 vs ≥5 years ago (for somewhat agree/strongly agree combined).

Figure 9. Beliefs about medical care after NET diagnosis and room for improvement in diagnosing NETs.



Question: To what extent do you agree or disagree with the following statements?

Figure 10. Desired improvements to NET diagnosis.



Question: Which of the following, if any, would have helped you have a better experience with your NET diagnosis?

LIMITATIONS

- This global NET patient survey had several important limitations that might have affected results:
 - Potential recall bias
 - Standardized, validated quality-of-life assessments were not used
 - Recruitment was conducted primarily through patient advocacy groups (51%) and online sources (32%); this might have resulted in a potentially biased sample not fully representative of the heterogeneous NET population
 - Respondents were more likely to be highly engaged and motivated care seekers, including female patients or those with a poorer prognosis

CONCLUSIONS

- Results from this first large global survey of patients with NETs, including patients in the EU, demonstrated a substantial delay in NET diagnosis, consistent with findings in the literature,¹ and shed light on the extensive use of health care resources associated with establishing a NET diagnosis
- Improvements in time to diagnosis over the last 5 years suggest that awareness about NETs is increasing among physicians; however, many patients continue to be diagnosed with other conditions, some more than once, before receiving a NET diagnosis
 - A considerable need exists to diagnose NETs earlier in the disease course, thus improving survival
- HCP communications regarding NETs at the time of diagnosis have an important influence on how patients feel about their disease
- Patients identified several areas for improvement in the NET diagnostic process
 - They generally desired clearer, more detailed information on their disease and better access to NET resources and knowledgeable HCPs

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ACKNOWLEDGMENTS

- We thank the patients who participated in this survey and our patient advocacy partners throughout the world who contributed to this project, including Australia, The Unicorn Foundation, Belgium, vzw NET & MEN Kanker Belgium, Bulgaria, The Association of Cancer Patients and Friends (APOZ), Canada, Carcinoid-Neuroendocrine Tumour Society (CNETS) Canada, France, Association des Patients Porteurs de Tumeurs Endocrines Diverses (APTED), Germany, Netzwerk Neuroendokrine Tumoren, Japan, PanCAN Japan, New Zealand, Unicorn Foundation NZ, Norway, Carcinoid, Singapore, Carcinoid & Neuroendocrine Tumor Society (CNETS) Singapore, United Kingdom, NET Patient Foundation and The Association for Multiple Endocrine Neoplasia Disorders (AMEND), and United States, The Carcinoid Cancer Foundation and Caring for Carcinoid Foundation
- Medical editorial assistance for this poster was provided by ApotheCom (Yardley, PA) and was funded by Novartis Pharmaceuticals Corporation

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