

Neuroendocrine Tumor (NET) European (EU) Patient Experience: Results From the First Global NET Patient Survey—

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

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BACKGROUND

- Patients with NETs experience a wide spectrum of symptoms¹ and a reduced quality of life (QoL)
- A cross-sectional comparative analysis of 196 patients with NETs in Norway demonstrated significantly lower health-related QoL (HRQoL) scores in patients with NETs versus the general Norwegian population; lowest scores were found for the general health, physical limitation, and vitality HRQoL subscales²
- Despite the considerable impact NETs have on patients' daily lives, the journey for patients with NETs has rarely been documented; only a few small qualitative studies have been published to date (N <20)^{3,4}
- 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 goal of capturing individual patient experiences of living with NETs to increase understanding of the NET journey and the needs of patients with NETs
- We present data on quality of life and the EU NET patient perspective

OBJECTIVE

- To raise awareness of the NET-related burden and share patients' perspectives on NETs, medical team interactions, and educational needs

METHODS

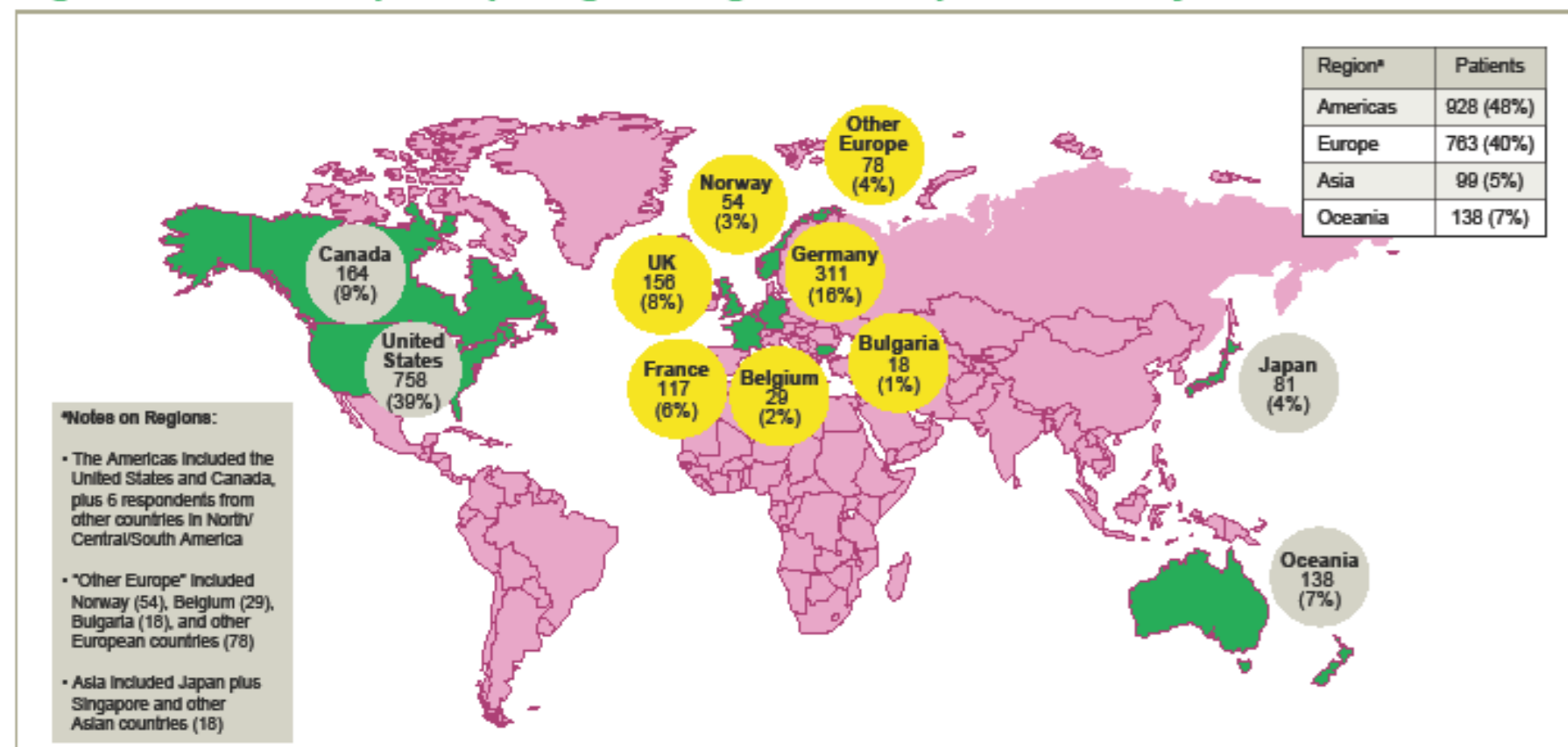
- From February through May 2014, patients with NETs participated in a 25-minute anonymous survey that captured the NET patient experience, including disease impact, medical team interactions, knowledge/awareness, and information needs
- With the exception of certain demographic information, survey questions 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
- The survey was primarily conducted online and was 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 professionals (HCPs) to reach patients without Internet access
- Data were analyzed at global, regional, and country levels; here we present results from EU data
- Statistical differences between comparisons were significant at the 95% confidence level (P <0.05)
- 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 population: All respondents (N = 1928). Question: In which country do you live? In which region do you live?

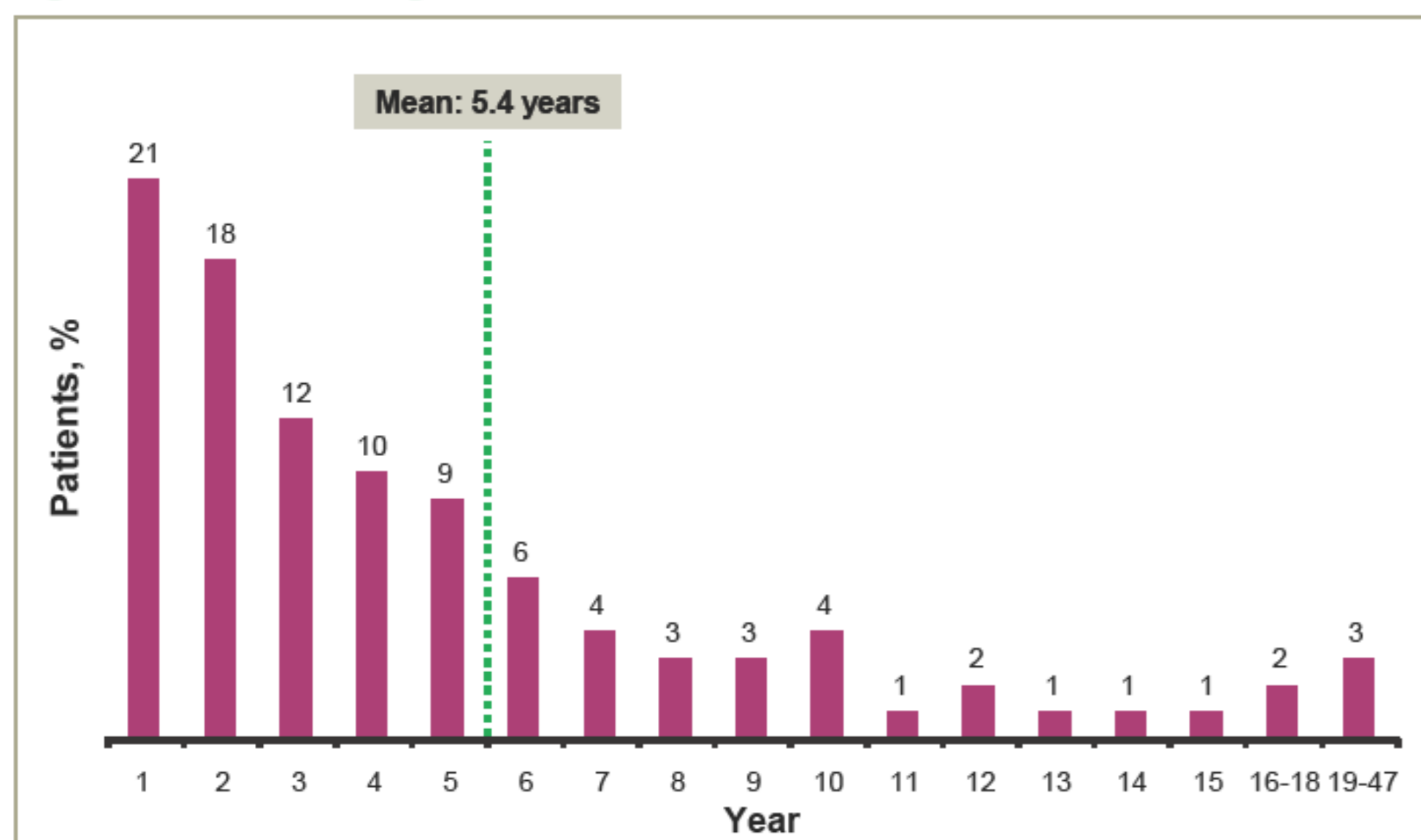
- The average age of EU patients was 58 years; 57% were female
- Gastrointestinal (GI) NET (53%) and pancreatic NET (pNET) (27%) were the most common subtypes reported among EU patients, followed by lung NET (10%), other (8%), thymus (1%), and unknown site (4%)
- Most patients had grade (G) 1 (41%) or G2 (26%) functional disease (44%) (Table 1)
- GI NETs were more likely than pNETs to be low grade (G1: 50% vs 32%) and functional (58% vs 23%)
- 61% of patients reported being diagnosed <5 years ago (Figure 2)
- 63% of NETs had metastasized at time of diagnosis (Figure 3)
- Rate was greater for patients with GI (71%) or pNETs (62%) than lung NETs (37%)
- Rate was greater for patients diagnosed <5 years (67%) versus ≥5 years ago (57%)
- 34% of patients were employed full or part time or were self-employed, 39% were retired, 18% were on medical disability, and 8% were not employed/homemaker/student

Table 1. Functional Status and Grade of NETs

Functional Status of NET		Grade of NET	
Functional NETs: Produces symptoms caused by the secretions of hormones (eg, flushing, diarrhea, wheezing, cramping)	44%	Low (Grade 1): NETs are relatively slow growing; Ki-67 index ≤2%	41%
Nonfunctional NETs: Does not secrete hormones; however, they may cause symptoms caused by tumor growth (eg, pain, intestinal blockage, bleeding)	17%	Intermediate (Grade 2): NETs have a less predictable, moderately aggressive course; Ki-67 index 3%-20%	26%
Asymptomatic NETs: Experience no symptoms	20%	High (Grade 3): NETs can be highly aggressive; Ki-67 index >20%	7%
Physician does not describe/discuss	13%	Physician did not give my NET a grade	16%
Don't remember	6%	Physician does not give grade or describe/discuss	7%
		Don't remember	4%

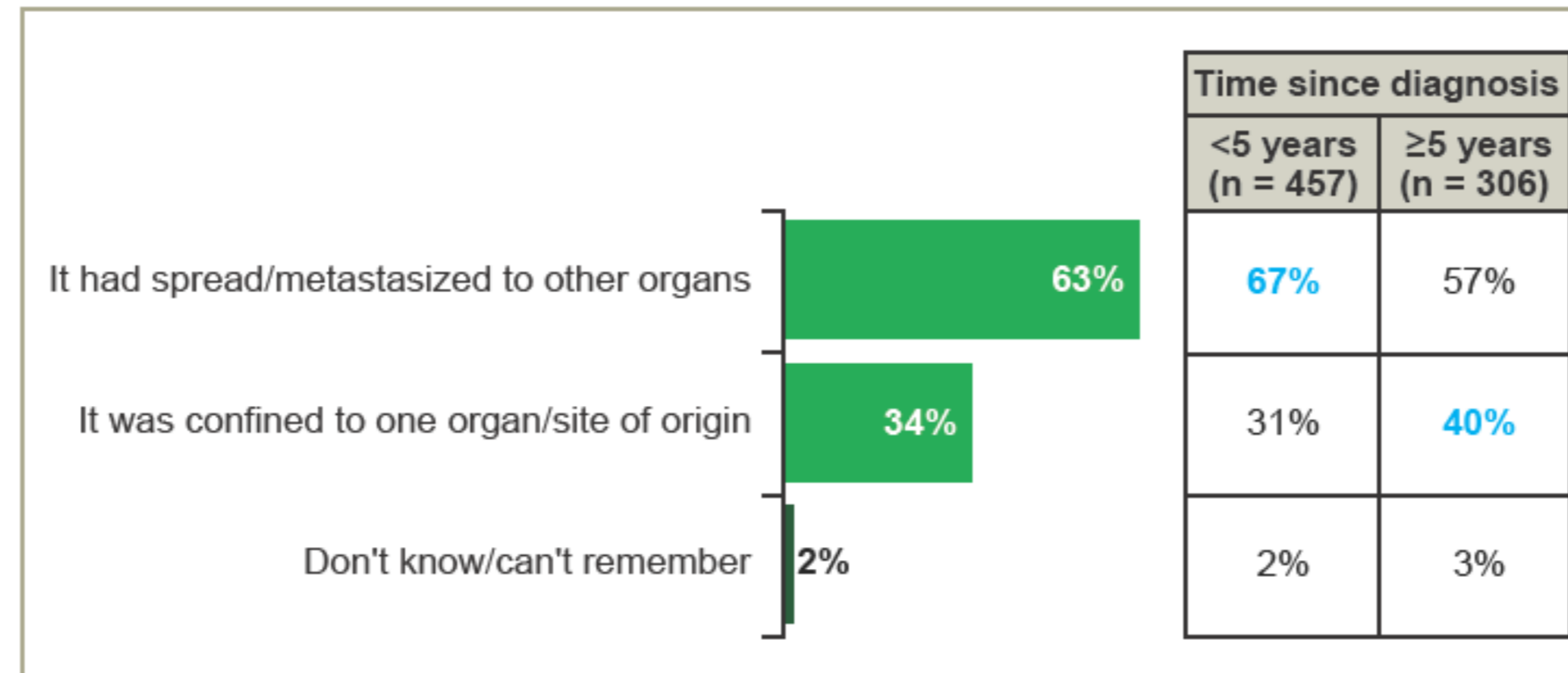
Questions: How, if at all, does your physician describe the functional status of your NET? Which of the following, if any, does your physician currently use to describe the grade of your NET?

Figure 2. Time since diagnosis.



Question: Approximately how many years ago were you first diagnosed with a NET?

Figure 3. State of tumor at time of diagnosis.

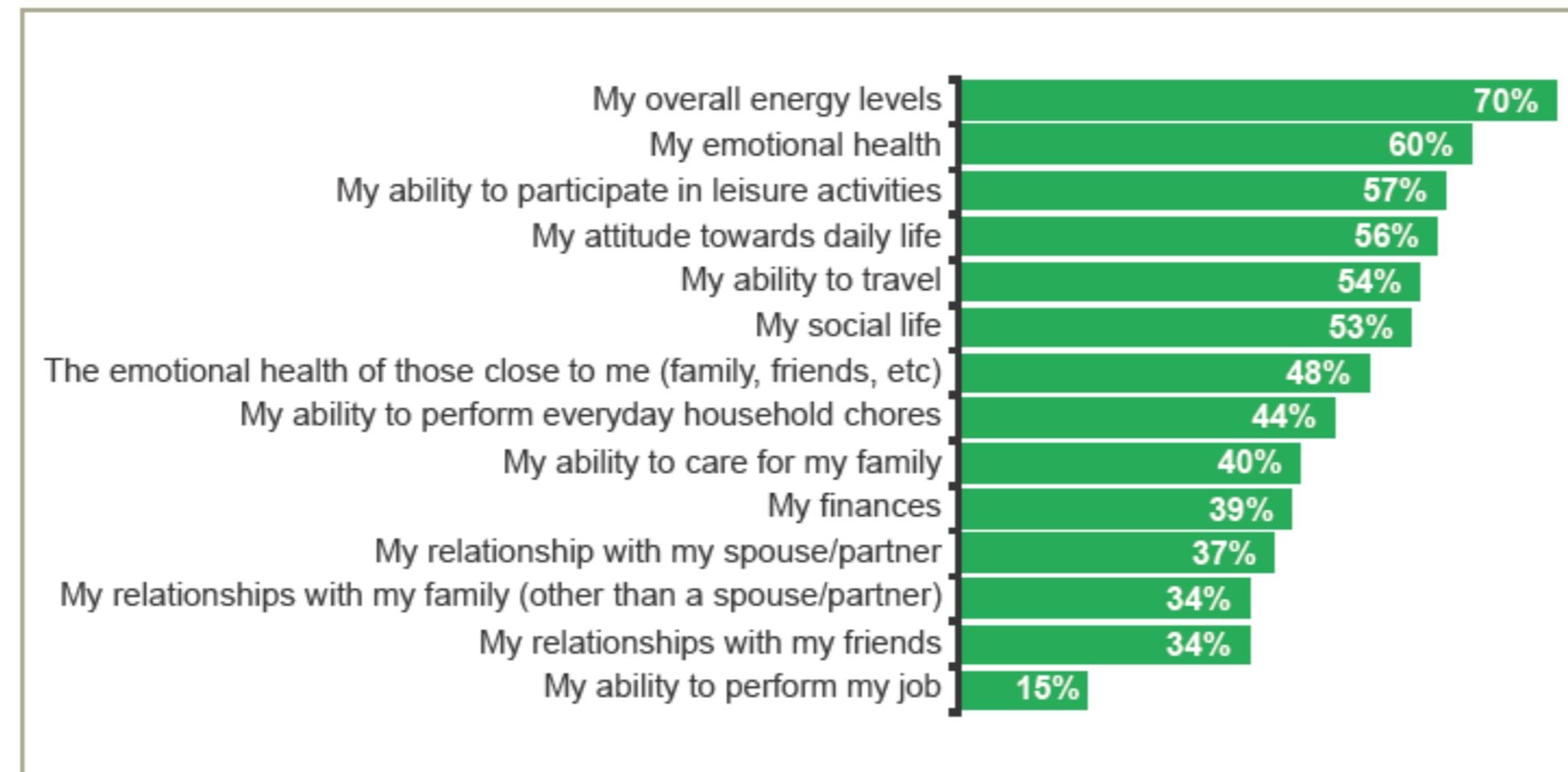


Question: Which of the following best describes your NET at the time of diagnosis? P <.05 for patients diagnosed <5 vs ≥5 years ago.

Impact of NETs on Patients' Daily Lives

- 41% of patients reported fair/poor health, and 72% reported that NETs had a negative impact on their lives, including overall energy levels (70%) and emotional health (60%) (Figure 4)
- Not surprisingly, respondents diagnosed <5 years ago were more affected emotionally by NETs than those diagnosed ≥5 years ago (64% vs 55%)
- Patients expressed many fear-related emotions with regard to NETs, including concerned, anxious/worried, uncertain, and scared

Figure 4. Negative impact of NETs on different aspects of life.



Question: How much has each of the following areas of your life been negatively affected, if at all, by your NET? Top 2 box scores shown (A moderate amount/A lot).

Support Received From Medical Team

- Patients felt well supported by their medical team, particularly endocrinologists (78%), nuclear medicine specialists (75%), and oncologists/nurses (74%/74%) (Figure 5)
- Though general practitioners (GPs)/primary care physicians (PCPs) were considered part of the health care team by more than half the patients, they were perceived as "very/extremely supportive" by a lower percentage of patients (60%) than other HCPs, including nurses and oncologists/hematologists
- Patients also felt that members of their medical team understood how NETs affect their lives, particularly oncologists (75%) and endocrinologists (74%) (Figure 6)
- GPs/PCPs, physician assistants, and pulmonologists were among the medical providers seen as having less understanding of the impact NETs have on patients

Figure 5. Support provided by specific HCP groups.

Group	Very/Extremely supportive	Somewhat supportive	Not supportive at all
Endocrinologist (n = 283)	78%	16%	4%
Nuclear medicine specialist (n = 292)	75%	17%	4%
Oncologist/hematologist (n = 425)	74%	22%	2%
Nurse/nurse practitioner (n = 237)	74%	23%	1%
GI specialist (n = 274)	72%	23%	4%
Surgeon (n = 154)	68%	19%	6%
Nutritionist (n = 41)	66%	27%	2%
GP/PCP (n = 486)	60%	30%	7%
Pulmonologist (n = 48)	54%	33%	6%
Physician assistant (n = 71)	51%	32%	13%

Question: Which of the following best describes the level of support you receive from each of the following in helping you deal with your NET?

Figure 6. HCP understanding of how NETs affect patients' lives.

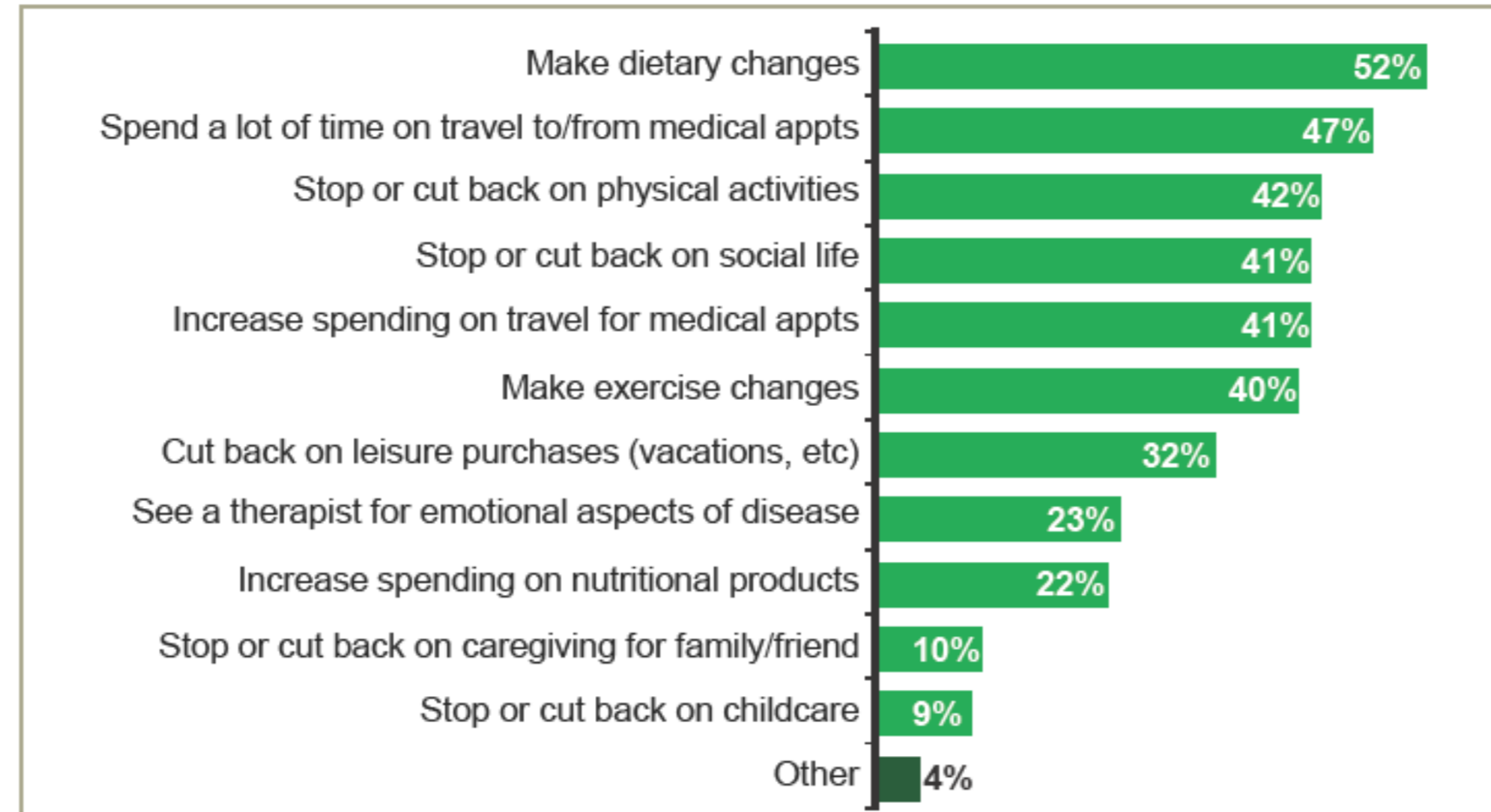
Group	Very/Extremely understanding	Somewhat understanding	Not at all understanding
Oncologist/hematologist (n = 425)	75%	20%	2%
Endocrinologist (n = 283)	74%	20%	2%
GI specialist (n = 274)	73%	21%	2%
Nuclear medicine specialist (n = 292)	70%	20%	3%
Surgeon (n = 154)	69%	21%	5%
Nutritionist (n = 41)	68%	22%	2%
Nurse/nurse practitioner (n = 237)	66%	30%	3%
GP/PCP (n = 486)	57%	36%	4%
Pulmonologist (n = 48)	54%	31%	6%
Physician assistant (n = 71)	42%	35%	13%

Question: To what extent do the following people understand how having a NET affects your life?

Lifestyle and Work-Related Changes Following a NET Diagnosis

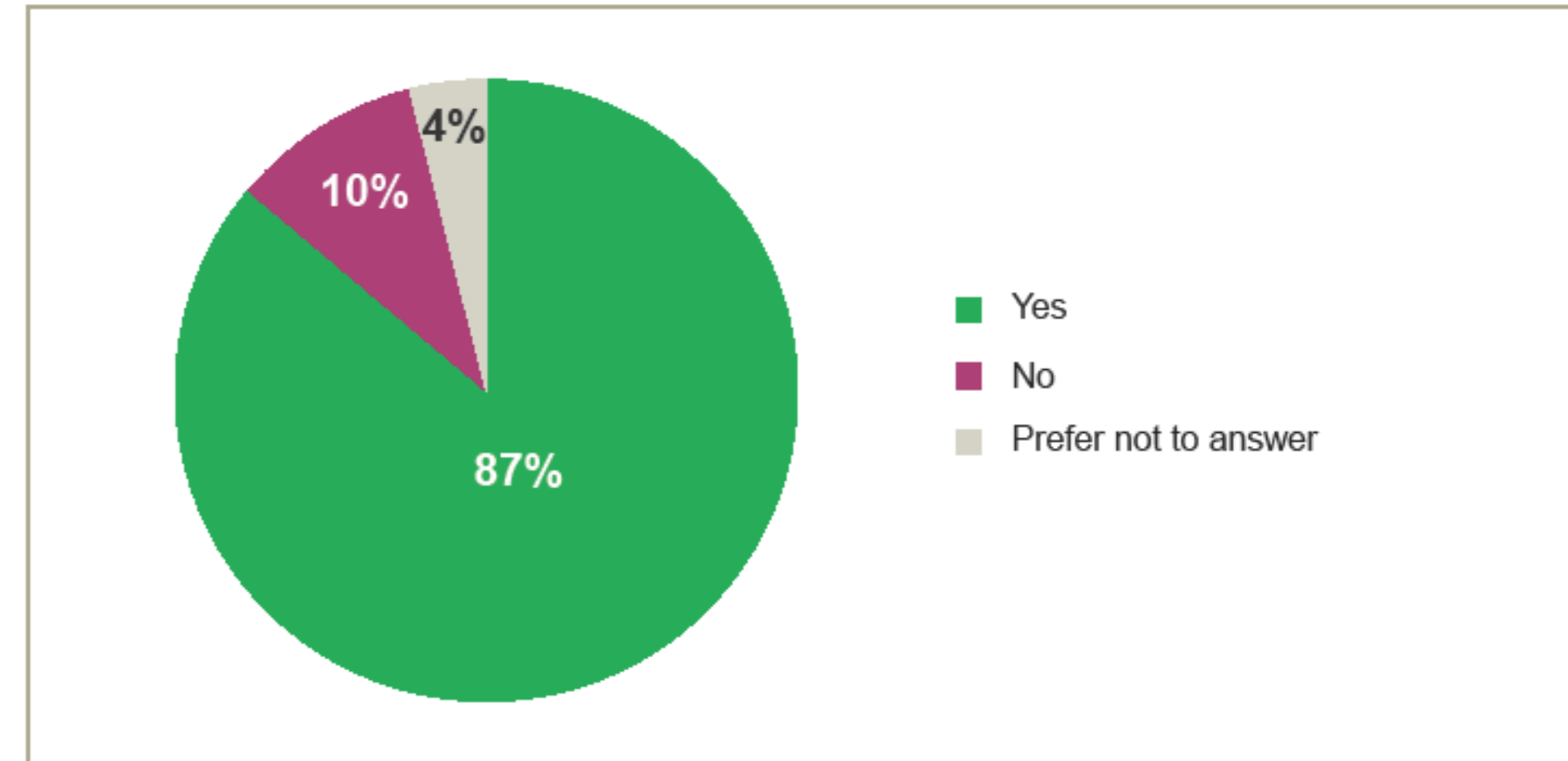
- Patients reported making several lifestyle and work-related changes following diagnosis:
 - Lifestyle-related changes included dietary modifications (52%) and increased travel (47%) or related spending (41%) for medical appointments (Figure 7)
 - Patients with lung NET (34%) were less likely than those with GI (54%) and pNET (55%) to make dietary modifications
- Work-related changes (among those working, n = 260) included having to stop working altogether for a period of time (32%), take days off work (30%), reduce work hours (27%), and ask employer to make accommodations (such as flexible work schedule, work from home, adaptive devices, opportunities for rest; 24%)
- Of patients who were not currently employed or not able to work because of medical disability (n = 163), 87% had to stop working as a direct result of their NETs (Figure 8)
- 30% of retirees (n = 295) had to stop working earlier than planned

Figure 7. Lifestyle changes caused by NETs.



Question: Since you were diagnosed with your NET, have you had to make any of the following changes? Please select all that apply.

Figure 8. Patients who had to stop working as a direct result of NETs.



Base population: EU respondents not currently employed or able to work because of medical disability (n = 163). Question: Have you had to stop working as a direct result of your NET?

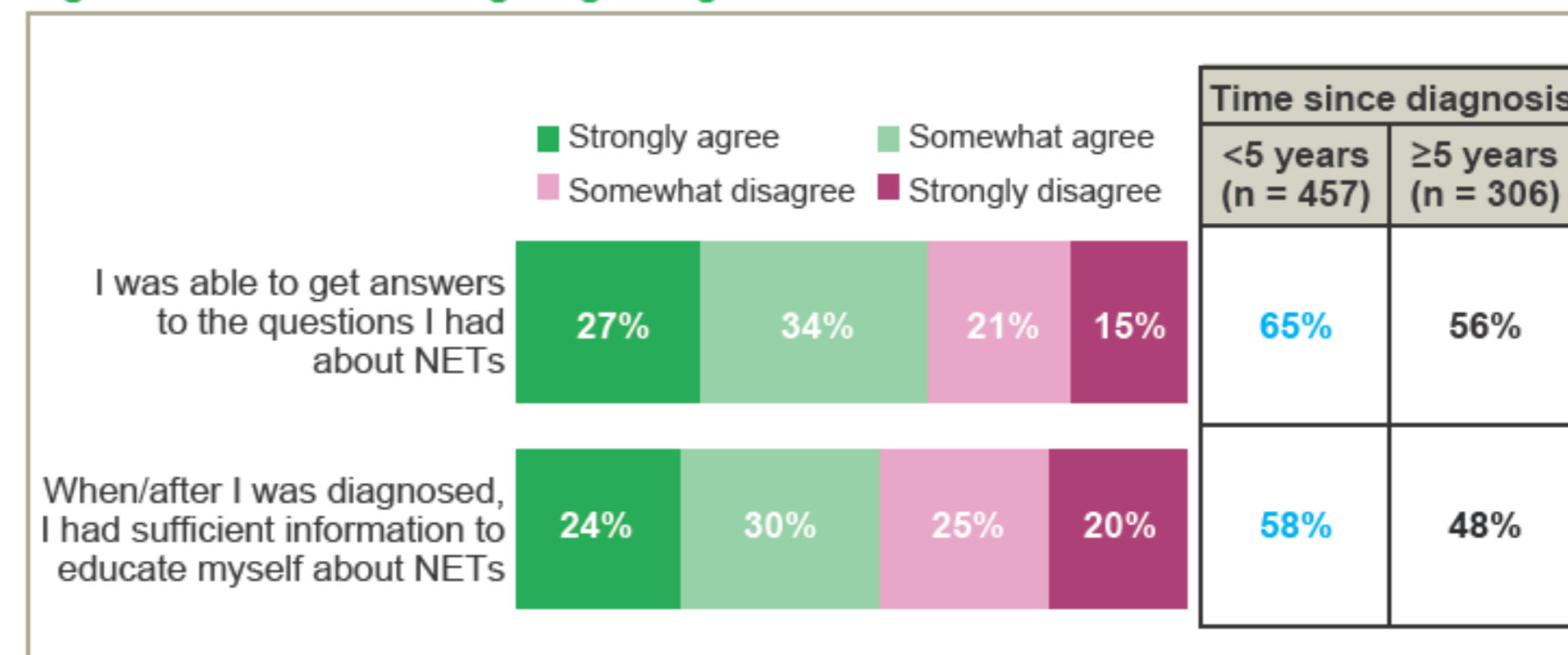
Patient Knowledge Regarding NETs

- 44% of patients felt they did not have sufficient information regarding NETs after their diagnosis, and 36% of patients were unable to get answers to their questions about NET (Figure 9)
- This occurred more frequently in patients diagnosed ≥5 years versus <5 years ago (Figure 9)
- Significantly more patients visiting a NET specialist center on a regular basis (≥1 visit/year) felt they received sufficient information to be educated about NETs compared with non-specialist center visitors (59% vs 46%)

Improvements to Enhance the Quality of Life of Patients With NETs

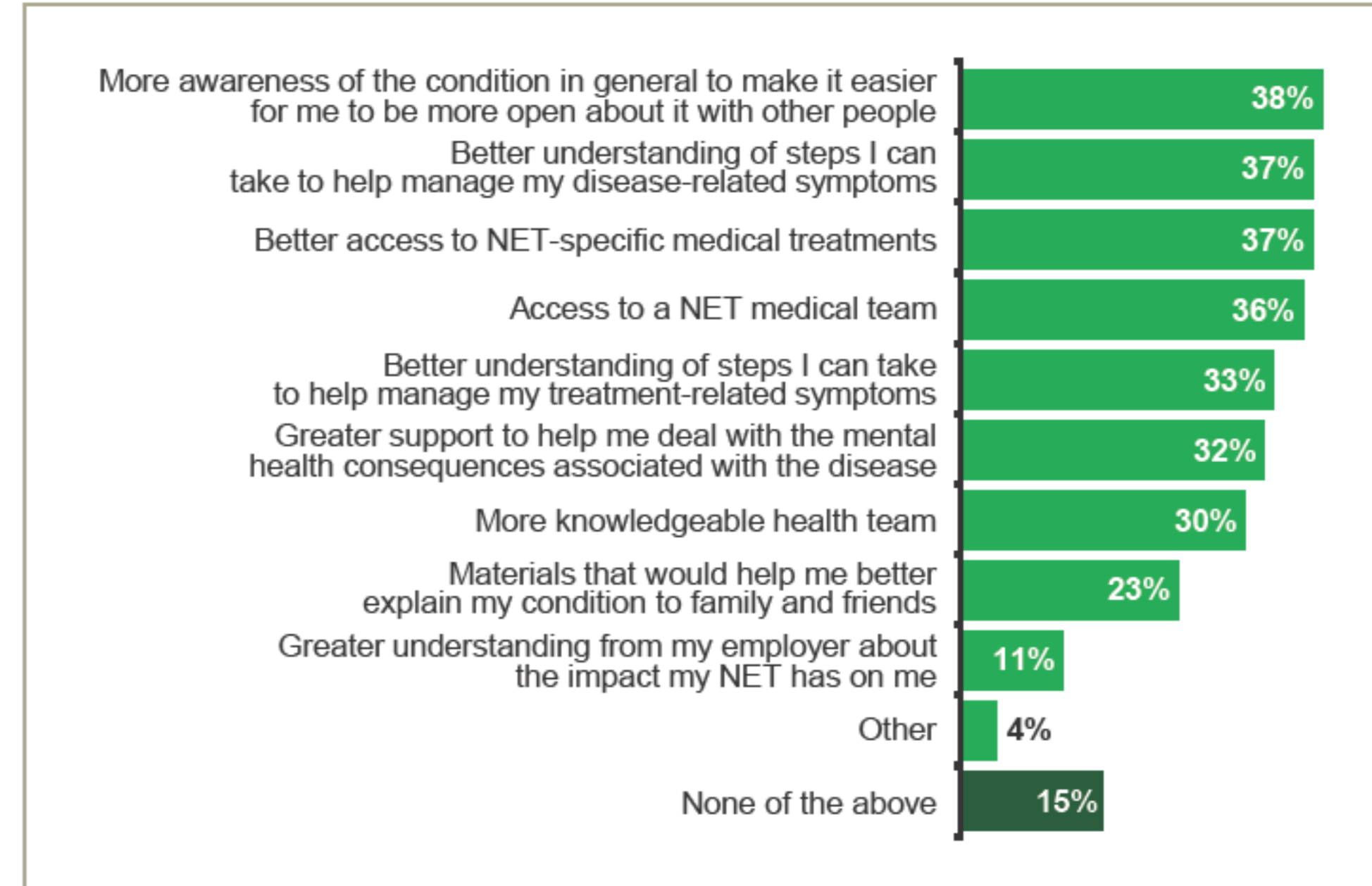
- Patients suggested various improvements that would help them live better with NETs, including more awareness of NETs (38%), information regarding how to manage disease-/treatment-related symptoms (37%/33%), and increased access to NET-specific treatments/medical teams (37%/36%) (Figure 10)

Figure 9. Patient knowledge regarding NETs.



Question: To what extent do you agree or disagree with the following statements? P <.05 for patients diagnosed <5 vs ≥5 years ago.

Figure 10. Improvements patients believed would help them live better with NETs.



Question: Which of the following, if any, would help you live with a NET?

LIMITATIONS

- This global NET patient survey had several important limitations that might have affected results:
 - Potential recall bias
 - Standardized, validated QoL 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 large global survey demonstrated that in the EU, similar to the global population, NETs have a large impact on patients' daily lives, including emotional health, interactions with friends and family, and ability to perform household tasks or travel
- Patients felt well supported by their NET medical teams, particularly endocrinologists, oncologists, nuclear medicine specialists, and nurses
- However, many patients felt they lacked sufficient information to educate themselves and others about NETs
- Numerous improvements were suggested, including:
 - Greater access to NET-specific medical teams/medical treatment
 - More awareness of how to manage disease- and treatment-related symptoms
 - Better access to informational materials about NETs

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