

The Neuroendocrine Tumor Patient Perspective: Results From the First Global NET Patient Survey—A Collaboration Between the International Neuroendocrine Cancer Alliance (INCA) and Novartis Pharmaceuticals

John Leyden,¹ Maia Sissons,² Grace Goldstein,³ Teodora Kolarova,⁴ Catherine Bouvier²

¹The Unicorn Foundation, Mosman, NSW, Australia; ²NET Patient Foundation, Hockley Heath, United Kingdom; ³The Carcinoid Cancer Foundation, Inc., White Plains, NY, USA; ⁴APOZ & Friends, Sofia, Bulgaria

BACKGROUND

- Neuroendocrine tumors (NETs) are a diverse group of rare neoplasms arising from neuroendocrine cells that have a heterogeneous disease course and remain poorly understood by many patients and health care providers (HCPs)¹
- Patients with NETs experience a wide spectrum of symptoms¹ and a reduced quality of life
 - In a US-based study of 633 patients with NETs utilizing an online health-related quality-of-life (HRQoL) survey, HRQoL scores were significantly worse for patients with NETs versus the general US population, particularly with regard to symptoms of diarrhea and flushing²
 - A cross-sectional comparative analysis of 196 patients with NETs in Norway demonstrated significantly lower HRQoL scores in patients with NETs versus the general Norwegian population; lowest scores were found for the general health, physical limitation, and vitality HRQoL subscales³
- 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)^{4,5}
- INCA is a network of 17 independent charitable organizations and patient groups from 14 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 living with NETs 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 data on quality of life and the global NET patient perspective

AIM

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

METHODS

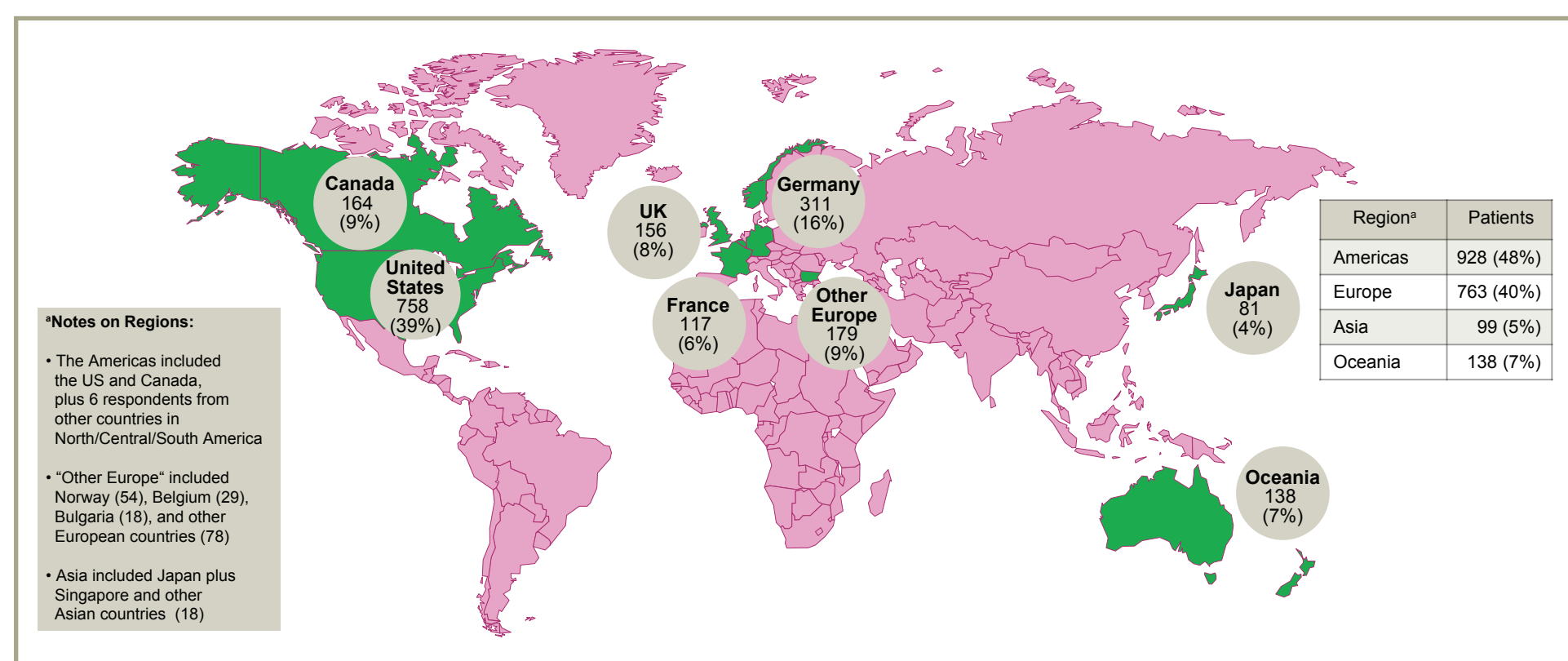
- From February through May 2014, patients with NETs participated in a 25-minute anonymous survey that captured the NET patient experience, including disease impact, medical team interactions, knowledge/awareness, and information needs
 - With the exception of certain demographic information, survey 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
 - Extensive use of online social media sources through local/regional advocacy groups allowed recruitment of a large number of patients with this rare type of cancer
- The survey was conducted primarily 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 HCPs to reach patients without Internet access
- Data were analyzed at global, regional, and country levels; here we present results from global data
 - Statistical differences between comparisons were significant at the 95% confidence level (P <0.05)
- 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, Europe, and Oceania (Figure 1)
- The majority of respondents were from Europe (n = 763) and North America (n = 922)

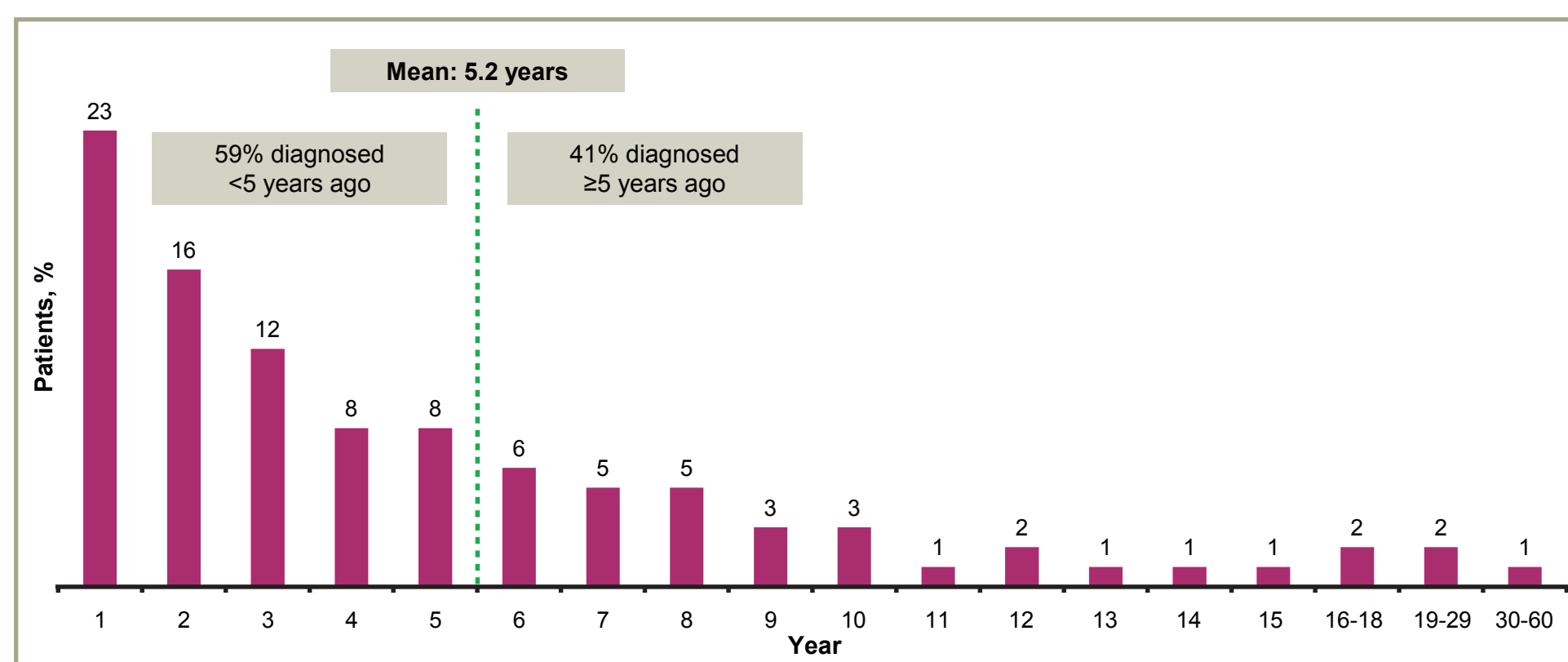
Figure 1. Countries participating in the global NET patient survey.



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

- Average age of patients was 56.8 years; 64% were female
- Gastrointestinal NET was the most common NET type (54%), followed by pancreas (22%), lung (12%), thymus (1%), other (8%), and unknown site (5%)
- Most patients had grade (G) 1 (37%) or G2 (21%), functional disease (44%) (defined as tumors that produce symptoms caused by the secretion of hormones, eg, flushing, diarrhea, wheezing, cramping)
- 60% of patients reported being diagnosed <5 years ago (Figure 2)
- 39% of patients were employed full or part time or were self-employed, 31% were retired, 18% were on medical disability, and 11% were not employed/homemaker/student

Figure 2. Time since diagnosis.

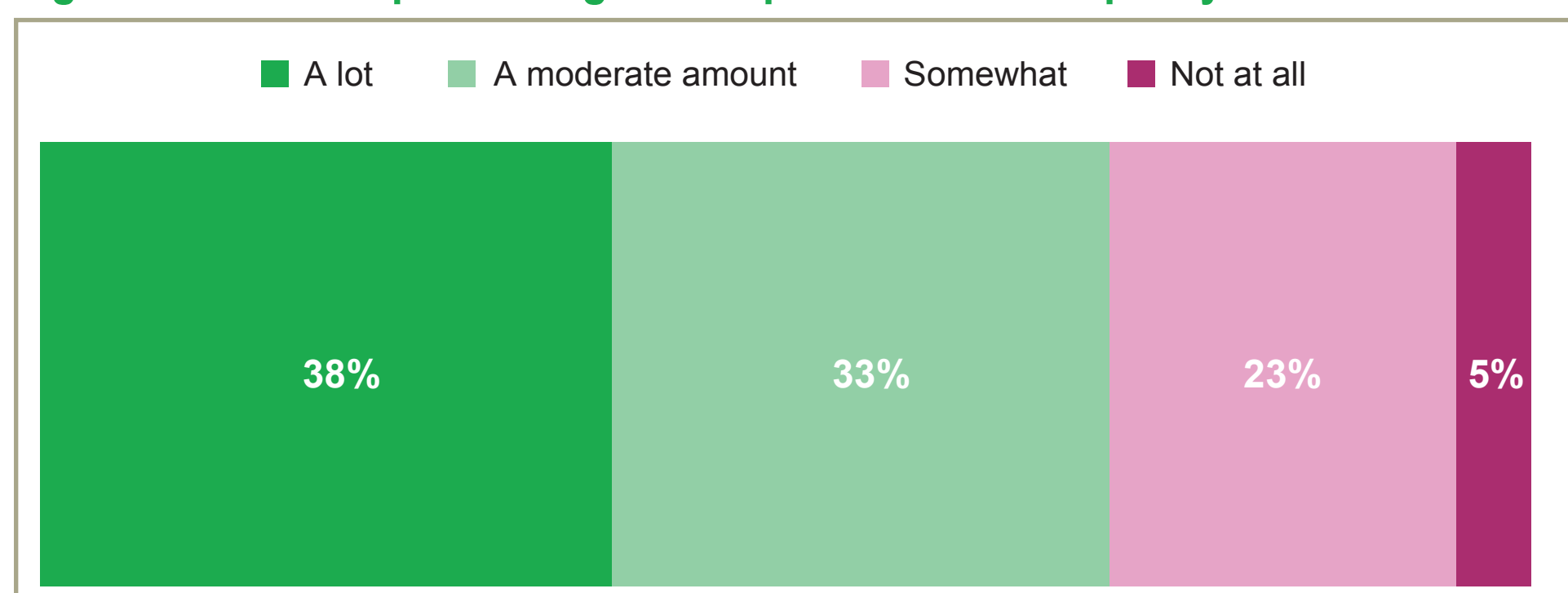


Base population: All respondents (N = 1928). Question: Approximately how many years ago were you first diagnosed with a NET?

Impact of NETs on patients' daily lives

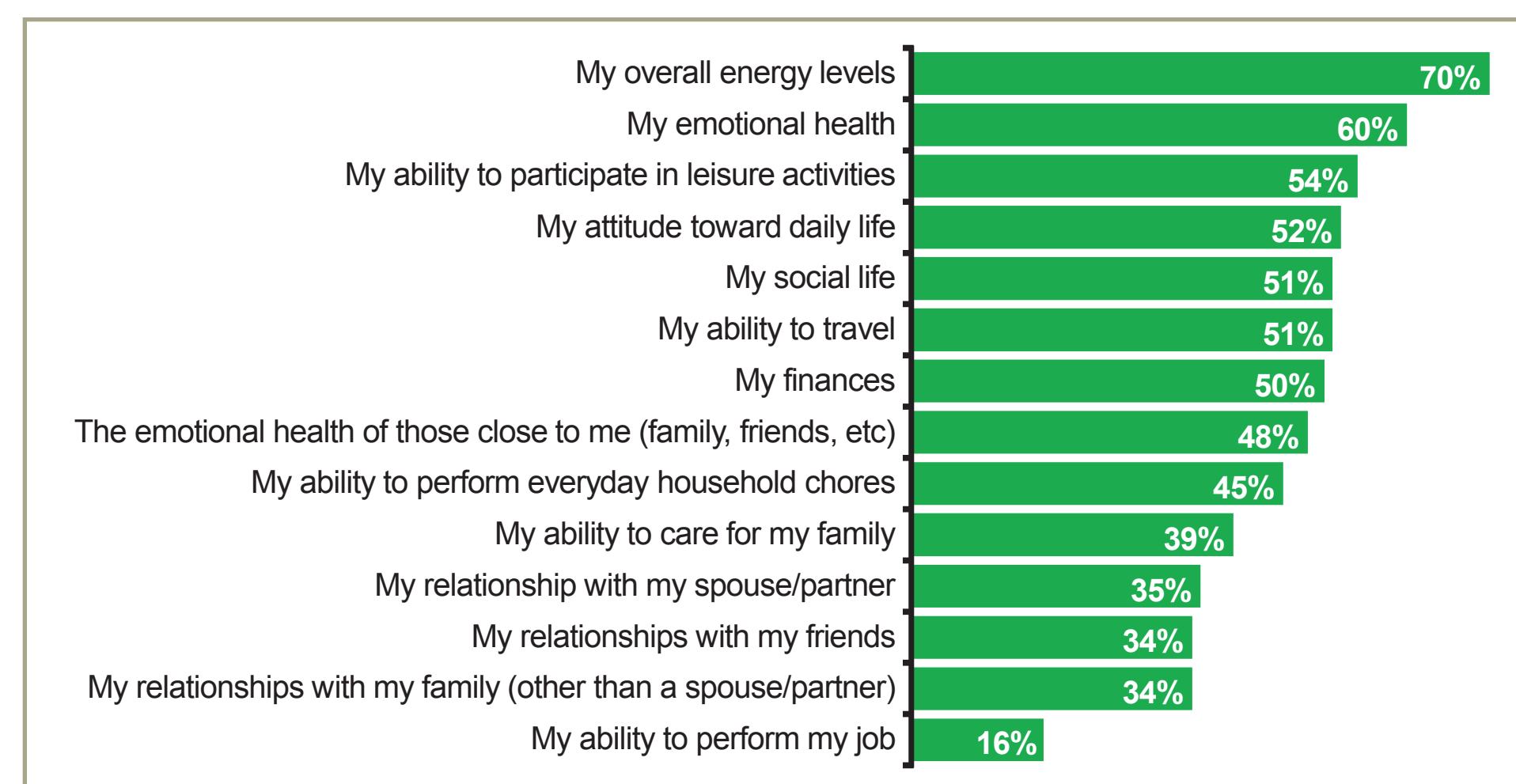
- 72% of patients reported a large to moderate negative impact of NETs on their quality of life (Figure 3), including overall energy levels (70%); their emotional health (60%) and that of close family/friends (48%); finances (50%); ability to care for household (45%) and family (39%); and relationships with spouse/partner (35%), friends (34%), and family (34%) (Figure 4)
- Patients diagnosed <5 years ago were more emotionally affected by NETs compared with those diagnosed ≥5 years ago (63% vs 56%)
- Patients expressed many fear-related emotions with regard to NETs, which lessened somewhat over time (diagnosed <5 vs ≥5 years ago)
 - Concerned: 55% vs 48%
 - Anxious/worried: 50% vs 42%
 - Uncertain: 45% vs 40%
 - Scared: 28% vs 20%

Figure 3. Patient-reported negative impact of NETs on quality of life.



Base population: All respondents (N = 1928). Question: How much of a negative impact, if any, has your NET had on your overall quality of life?

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



Base population: All respondents (N = 1928). 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 to lot).

Support received from medical team

- Patients felt well supported by their medical team, particularly by their oncologists (77%) and nurses/nurse practitioners (NPs) (78%), although only 28% listed nurses/NPs as part of their medical team (Figure 5)
- Though general practitioners (GP)/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 (65%) than other HCPs, including nurses and oncologists/hematologists
- Patients did not feel as well supported by HCPs in general compared with members of their NET medical team
- Patients also felt that members of their medical team understood how NETs affect their lives, particularly oncologists (74%) and nurses/NPs (71%) (Figure 6)
- GPs/PCPs and HCPs in general were among the medical providers seen as having the least understanding of the impact NETs have on patients

Figure 5. Support provided by HCPs.

Group	Very/extremely supportive	Somewhat supportive	Not supportive at all	HCPs involved in the NET medical team (N = 1928)*
Nurse/nurse practitioner (n = 541)	78%	20%	1%	28%
Oncologist/hematologist (n = 1348)	77%	20%	3%	70%
Surgeon (n = 588)	75%	17%	4%	30%
Nuclear medicine specialist (n = 569)	74%	19%	3%	30%
Endocrinologist (n = 555)	74%	20%	4%	29%
GI specialist (n = 634)	71%	23%	3%	33%
Nutritionist (n = 128)	67%	25%	2%	7%
Physician assistant (n = 202)	66%	26%	6%	10%
GP/PCP (n = 1112)	65%	30%	4%	58%
Pulmonologist (n = 151)	61%	30%	6%	8%
HCPs in general (n = 1928)	45%	42%	6%	-

GI, gastrointestinal. Base population: All respondents (number varies by category). 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? *Other, 9%.

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

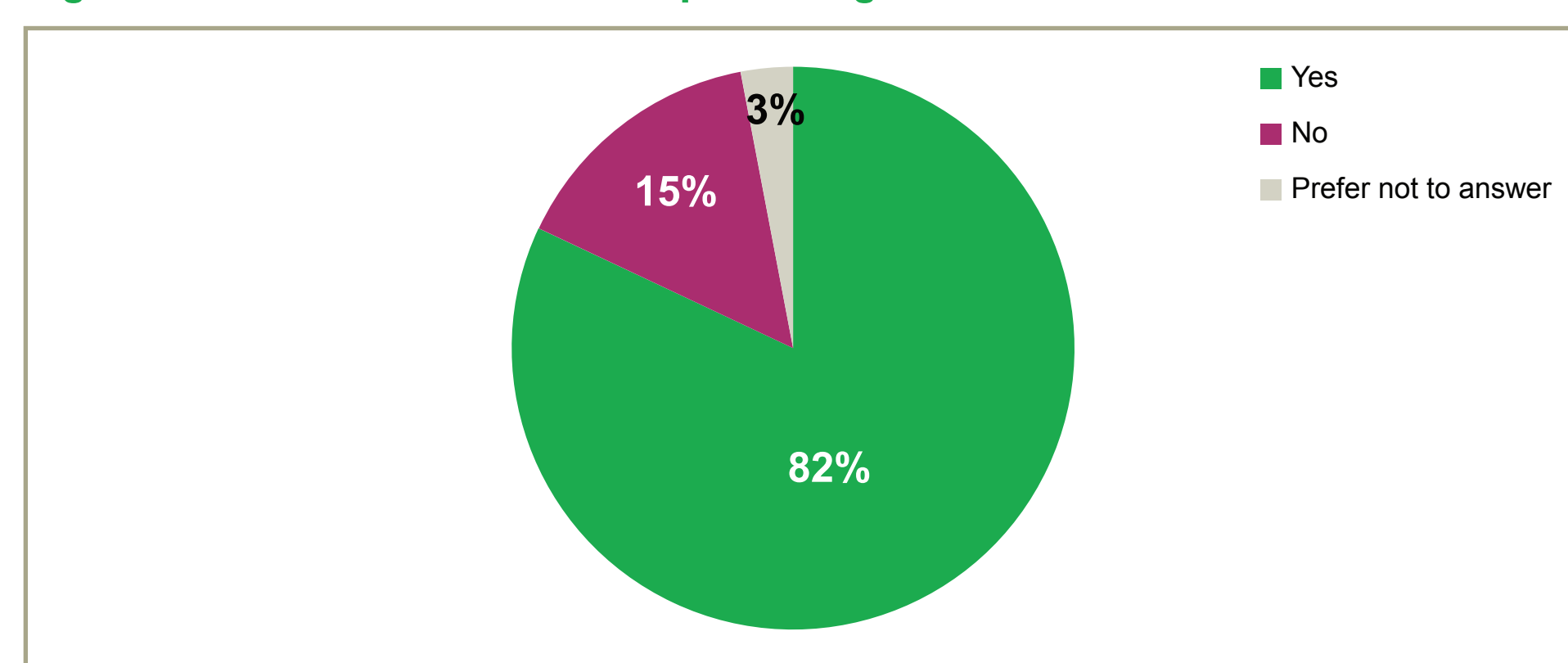
Group	Very/extremely understanding	Somewhat understanding	Not at all understanding	HCPs involved in the NET medical team (N = 1928)*
Oncologist/hematologist (n = 1348)	74%	21%	3%	70%
Nurse/nurse practitioner (n = 541)	71%	25%	3%	28%
Surgeon (n = 588)	70%	23%	4%	30%
Endocrinologist (n = 555)	69%	24%	3%	29%
GI specialist (n = 634)	68%	24%	4%	33%
Nuclear medicine specialist (n = 569)	68%	23%	3%	30%
Physician assistant (n = 202)	61%	30%	6%	10%
Nutritionist (n = 128)	60%	29%	3%	7%
GP/PCP (n = 1112)	57%	37%	4%	58%
Pulmonologist (n = 151)	57%	34%	6%	8%
HCPs in general (n = 1928)	34%	48%	13%	-

Base population: All respondents (number varies by category). Question: To what extent do the following people understand how having a NET affects your life? *Other, 9%.

Lifestyle and work-related changes following a NET diagnosis

- Patients reported making several lifestyle and work-related changes following diagnosis:
 - Lifestyle changes included diet modifications (58%), time/money for travel to medical appointments (52%/51%), and limited physical activity/social life (49%/43%)
 - Work-related changes (among those working, n = 741) included days off work (49%), asked employer to make accommodations (flexible work schedule, work from home, adaptive devices, opportunities for rest) (27%), reduced work hours (24%), and stopped working altogether for a period of time (24%)
- Of patients who were not currently employed or not able to work because of medical disability (n = 440), 82% had to stop working as a direct result of their NETs (Figure 7)

Figure 7. Patients who had to stop working as a direct result of NETs.

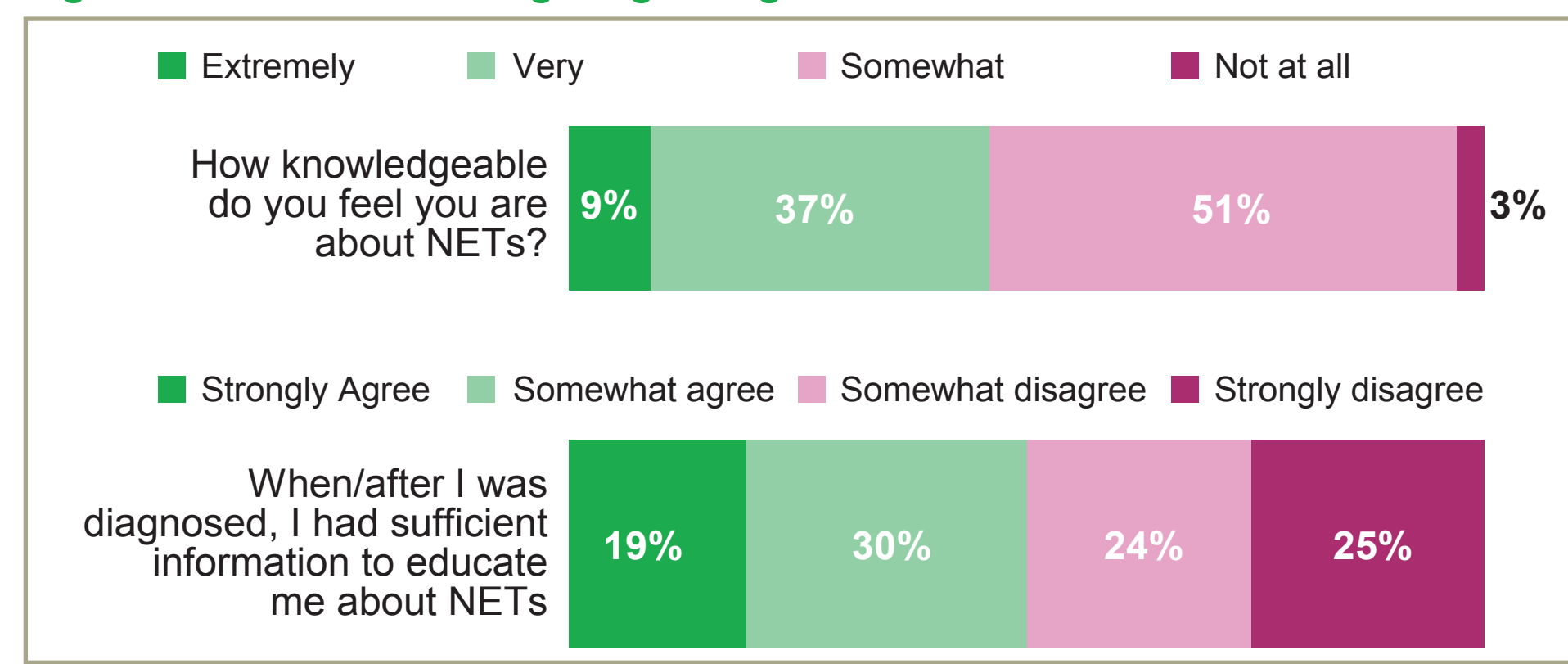


Base population: Respondents who are not currently employed or not able to work because of medical disability (n = 440). Question: Have you had to stop working as a direct result of your NET?

Patient knowledge regarding NETs

- 54% of patients felt only somewhat or not at all knowledgeable about NETs (Figure 8)
- Not surprisingly, patients diagnosed ≥5 years ago vs more recently (<5 years) reported feeling more knowledgeable regarding NETs (51% vs 42%), as did those who visited a specialist center at least once per year (53% vs 37%)
- 49% felt they did not have sufficient information regarding NETs after their diagnosis (Figure 8)
- 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 (54% vs 45%)

Figure 8. Patient knowledge regarding NETs.



Base population: All respondents (N = 1928). Question: How knowledgeable do you feel you are about NETs? Question: To what extent do you agree or disagree with the following statements?

Improvements to enhance the QoL of patients with NETs

- Patients suggested various improvements that would help them live better with NETs, including
 - Better access to NET-specific medical team/medical treatments (43%/46%)
 - More awareness of NETs in general (42%)
 - More awareness of how to manage treatment-related/NETs-related symptoms (37%/41%)
 - More knowledgeable health team (37%)
 - Greater support to deal with associated mental health consequences (35%)
 - Materials that help explain NETs to family/friends (31%)
- Resources on treatment-related side effects (80%), including management information (78%), were seen as the most useful in addition to resources for talking with HCPs (78%) (Figure 9)
- Patients who visited a specialist center (≥1 visit/year) had greater access to and satisfaction with available patient resources

Figure 9. Patient access to and usefulness of NET resources.

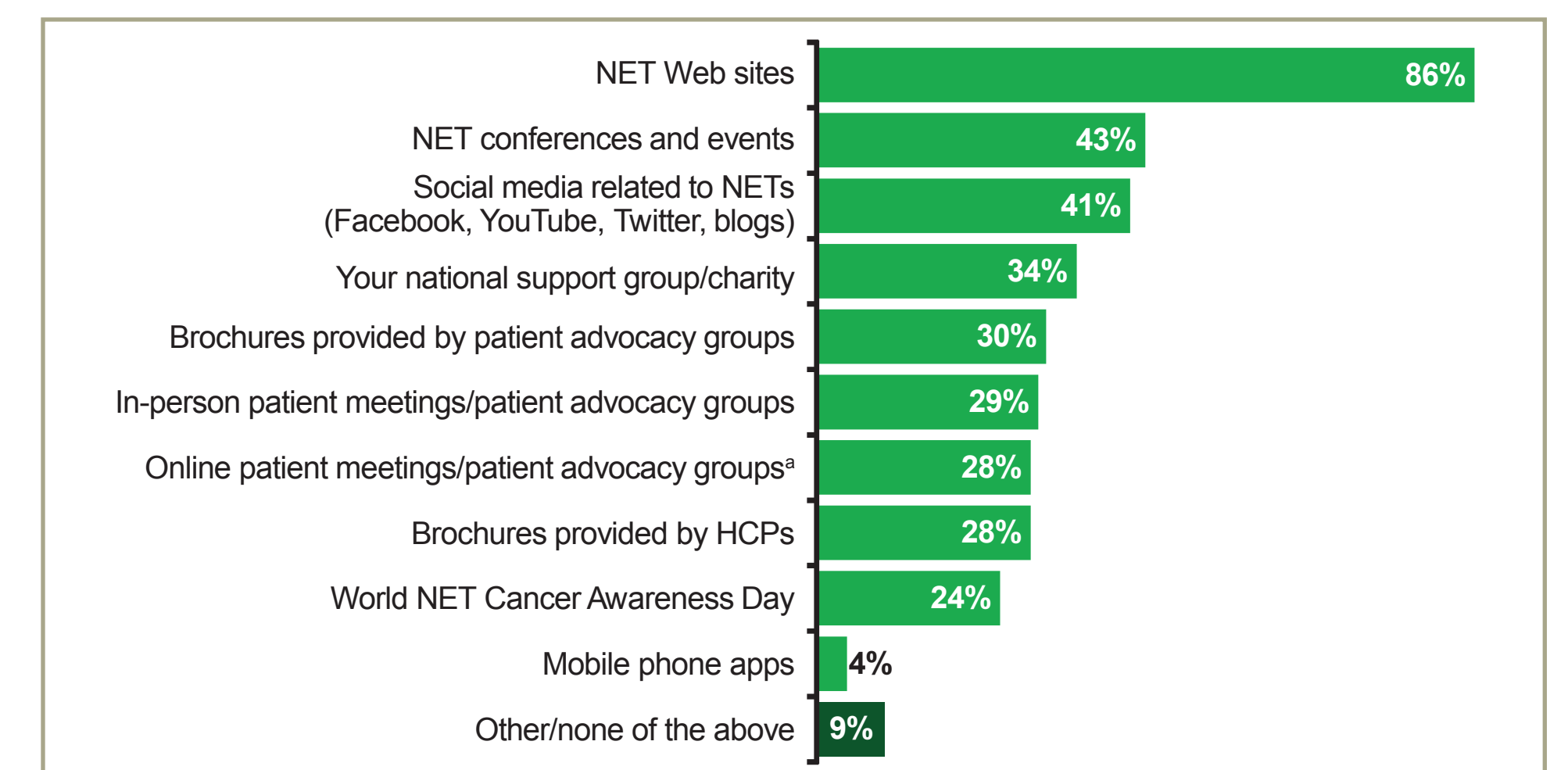
Resource	Not available		Available		
	Would not be useful	Would be useful	Not useful	Somewhat useful	Very useful
Tools to help maintain medication schedules	10%	23%	6%	18%	7%
Resources to help my friends and family cope with and understand my NET	6%	34%	5%	28%	9%
Resources for talking with HCPs	3%	35%	4%	28%	15%
Information about side effects of treatment	2%	26%	4%	35%	18%
Information on how to manage side effects of treatment	2%	31%	4%	33%	14%
Information about clinical trials	4%	39%	5%	26%	10%

Base population: All respondents (N = 1928). Question: Which of the following best describes your access to and impressions of each of the following today?

Information sources patients used to learn about NETs

- Respondents used a variety of sources to learn about NETs, especially Web sites (Figure 10)
- Patients who visited a NET specialty center at least once per year were more likely to seek information from most of these sources
- Many patients desired improvements in NET information following diagnosis, particularly
 - Clearer information regarding the long-term impact of NETs (60%)
 - Better direction on where to find useful NET information (52%)
 - A clearer idea of treatment options available (45%)
 - Clearer information on the diagnostic tests given (33%)

Figure 10. Sources of NET information used by patients.



Base population: All respondents (N = 1928). Question: Beyond your medical team, which of the following sources, if any, do you use to learn about NET? *This number is likely higher as some of those connecting to patient advocacy groups online might have only selected "NET Web sites."

LIMITATIONS

- This global NET patient survey had several important limitations that may have impacted results:
 - A patient-reported design was employed without independent verification, leading to potential recall bias
 - This survey did not utilize standardized, validated quality-of-life assessments
 - Recruitment was conducted primarily through patient advocacy groups (37%) and online sources (51%), which may have resulted in a potentially biased sample not fully representative of the heterogeneous NET patient population
 - Respondents were more likely to be highly engaged and motivated care seekers, including female patients and/or those with a poorer prognosis

CONCLUSIONS

- This large global survey of patients with NETs demonstrated that 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 oncologists/hematologists and nurse practitioners
 - However, many patients with NETs felt only somewhat or not at all knowledgeable about NETs, although this was less frequent in patients who visited specialist centers compared with non-specialist center visitors
- Patients utilized a wide spectrum of resources (particularly Web sites, NET conferences, and social media) and provided insights regarding additional information that would be useful. Numerous improvements were suggested, including:
 - Greater access to NET-specific medical teams/medical treatment
 - More awareness of how to manage symptoms (including treatment-related side effects)
 - Better direction on where to find useful NETs information

REFERENCES

- Vinik AI, et al. *Pancreas*. 2010;39(6):713-734.
- Beaumont JL, et al. *Pancreas*. 2012;41:461-466.
- Haugland T, et al. *Qual Life Res*. 2009;18(6):719-726.
- Feinberg Y, et al. *Eur J Oncol Nurs*. 2013;17(5):541-545.
- Griffiths J, et al. *Eur J Oncol Nurs*. 2007;11(5):434-441.

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, Carcinoid & Neuroendocrine Tumour Society (CNETS) Singapore, United Kingdom, NET Patient Foundation and The Association for Multiple Endocrine Neoplasia Disorders (AMEND); 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

Mobile Friendly e-Prints 3 ways to instantly download an electronic copy of this poster to your mobile device or e-mail a copy to your computer or tablet

Text Message (SMS)
Text: 09db95
to: 8NOVA (86682) US Only
+18324604729 North, Central and South Americas;
Caribbean; China
+447860024038 UK, Europe & Russia
+46737494608 Sweden, Europe

Visit the web at:
<http://novartis.medicalcongressposters.com/Default.aspx?doc=9db95>