

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

Kjell Öberg,¹ John Leyden,² Maia Sissons,³ Teodora Kolarova,⁴ Grace Goldstein⁵

¹Uppsala University Hospital, Uppsala, Sweden; ²The Unicorn Foundation, Mosman, NSW, Australia; ³NET Patient Foundation, Hockley Heath, United Kingdom; ⁴APOZ & Friends, Sofia, Bulgaria; ⁵The Carcinoid Cancer Foundation, Inc., White Plains, NY, USA

BACKGROUND

- Neuroendocrine tumors (NETs) are a diverse group of malignancies that arise from neuroendocrine cells throughout the body¹
- Symptoms of NETs may be nonspecific or absent until more advanced stages,¹⁻³ often leading to long delays in diagnosis^{1,3}
 - NET-related symptoms may persist for a median of 9 years before a NET diagnosis
- Due to the nonspecific nature of symptoms, patients with NETs may be seen by multiple specialists and undergo duplicate testing, leading to varying and potentially conflicting treatment recommendations and contributing to delays in diagnosis^{4,5}
- Multidisciplinary team (MDT) care at a center that specializes in NETs is supported by international NET treatment guidelines^{6,7} and aims to improve access to care and encourage coordinated care delivery⁸
 - Health care providers (HCPs) from different disciplines (eg, surgery, endocrinology, gastroenterology, clinical oncology, radiology, pathology) collaborate in determining a streamlined management plan, including diagnostic tests and treatment options⁹
- 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 the global NET patient perspective regarding MDT care

AIM

- To assess the patient perspective on NET management and interactions with HCPs

METHODS

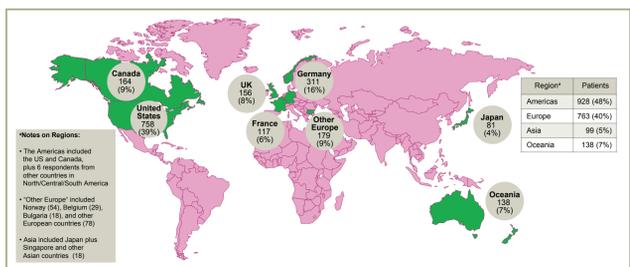
- From February through May 2014, patients with NETs participated in a 25-minute anonymous survey that captured the NET patient experience, including perceived benefits of an MDT care approach
 - With the exception of certain demographic information, survey questions were closed-ended; participants were 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
- This 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 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 ($P < 0.05$) for all statements within the text; statistically significant differences within figures are indicated by blue text
- 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.

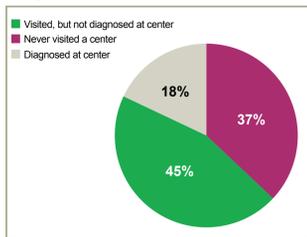


Base population: All respondents (N = 1928). Question: In which country do you live? Question: In which region do you live?

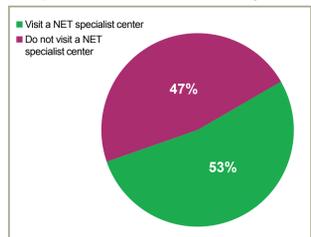
- The average patient age was 56.8 years; 64% were female
- The most common NET type reported by patients was gastrointestinal (54%), followed by pancreatic (22%), lung (12%), thymic (1%), other (8%), and unknown site (5%)
- Most patients reported they had grade (G)1 (37%) or G2 (21%) functional disease (44%) (defined as tumors that produce symptoms caused by the secretion of hormones, eg, flushing, diarrhea, wheezing, cramping)
 - Approximately one-third of patients did not know their NET grade: physician did not provide a grade (23%), physician does not provide or discuss tumor grades (9%), or patient did not remember (3%)
 - This was significantly less likely for patients who receive regular care at a NET specialist center (at least 1 visit/year): 26% versus 39%
- The majority of patients (63%) had visited a NET specialist center (Figure 2A). Approximately half (53%) visited at least once a year (Figure 2B); the mean was 4.3 visits/year (range, 0-45) among those who visited a specialist center
 - Patients diagnosed at a NET specialist center (n = 355) were more likely to visit a center for care (≥1 visit/year, 80%) than those not diagnosed at a center (n = 1559; ≥1 visit/year, 48%)
- Most patients (65%) had a caregiver (close family member or friend) who helped them manage day-to-day tasks associated with caring for their NET (including accompanying them to doctors' visits and helping make treatment decisions)

Figure 2. NET specialist center visits.

A. Patients who have been to a NET specialist center at least once



B. Patients who visit a NET specialist center at least once/year

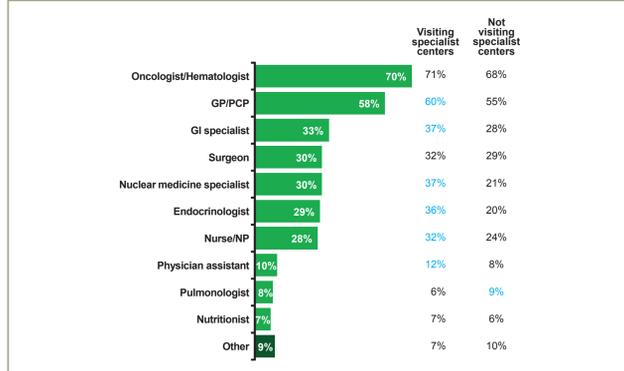


Base population: All respondents (N = 1928). Question: Have you ever been to a medical center that specializes in NET and has a team of different HCPs to help manage your NET? Question: Did you receive your NET diagnosis at a medical center that specializes in NET?

HCP interactions

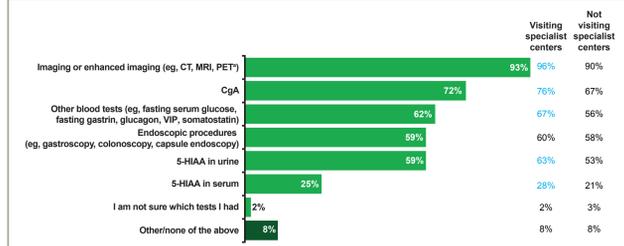
- A wide spectrum of HCPs are involved in managing patients with NETs (Figure 3)
 - Patients saw a median of 3 different HCPs for ongoing NET care
 - The average (median) time between HCP visits was
 - 1 month for physician assistants and nurses
 - 3 months for primary care physicians and oncologists
 - 6 months for specialists such as endocrinologists, surgeons, gastroenterologists, and pulmonologists
- Patients who visited a NET specialist center at least once/year traveled more than twice the distance to see their NET medical team compared with those who did not (mean distance 165 miles versus 77 miles)
- NET specialist center visitors saw a wider range of HCPs (Figure 3), received a wider range of tests/year (mean 5.8, vs 5.1) (Figure 4), and discussed a broader range of NET-related topics than non-specialist center visitors, including new treatment options and research developments (Figure 5)
- They were also more likely to be open about their NETs than non-specialist center visitors, including with close friends, relatives, and co-workers/acquaintances

Figure 3. HCPs involved in the NET medical team.



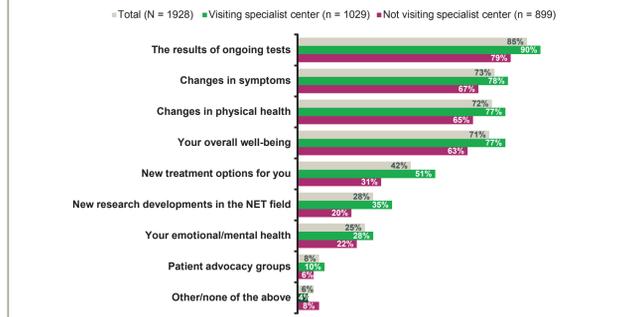
GI, gastrointestinal; NP, nurse practitioner; PCP, primary care physician. Base population: All respondents (N = 1928). Question: Which of the following HCPs are involved in the ongoing management of your NET? Please select all that apply. Blue text indicates significant differences between visitors to specialist centers versus non-specialist center visitors, $P < 0.05$.

Figure 4. Tests received for ongoing management of NETs.



5-HIAA, 5-hydroxyindoleacetic acid; CgA, chromogranin A; VIP, vasoactive intestinal peptide. Base population: All respondents (N = 1928). Question: Which of the following tests, if any, have you received for the ongoing management of your NET? "Imaging examples: Computed tomography (CT), magnetic resonance imaging (MRI), positron emission tomography (PET), somatostatin-receptor scintigraphy (Octreoscan), PET/CT with Ga68, F-DOPA scan, FDG PET/CT, MIBG scan." Blue text indicates significant differences between visitors to specialist centers versus non-specialist center visitors, $P < 0.05$.

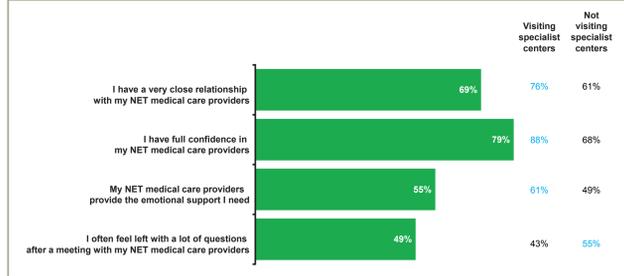
Figure 5. Topics discussed with NET medical providers.



Base population: All respondents (N = 1928). Question: Which of the following, if any, do you discuss at these meetings with your NET medical care providers?

- Visitors to NET specialist centers reported better HCP relationships (Figure 6) and were more likely to feel their HCPs functioned as a well-coordinated team (60% vs 36%) and want to work in partnership with their medical team than non-specialist center visitors (57% vs 48%)

Figure 6. Patient view on relationship with NET medical providers.

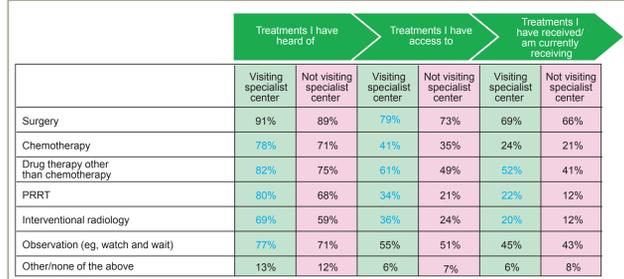


Base population: All respondents (N = 1928). Question: To what extent do you agree or disagree with the following statements? Top 2 box scores shown (Somewhat agree/Strongly agree). Blue text indicates significant differences between visitors to specialist centers versus non-specialist center visitors, $P < 0.05$.

Medical treatments

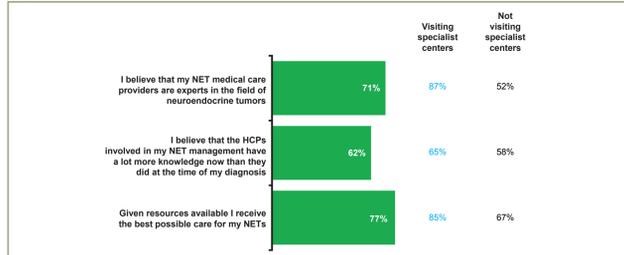
- Patients visiting NET specialist centers were more likely than non-specialist center visitors to rate the quality of NET-related treatments as good/very good (66% vs 46%), had access to a wider range of treatments (particularly nonchemotherapy agents, Figure 7), and were more likely to believe they received the best possible care (85% vs 67%) (Figure 8)
- Visitors to NET specialist centers were more likely than non-specialist center visitors to participate in clinical trials (48% vs 36%)

Figure 7. NET treatment availability.



PRRT, peptide receptor radionuclide therapy or targeted radiation therapy. Base population: All respondents (N = 1928). Question: This is a list of available NET treatments. Please select those you have heard of, those you have access to (meaning they are available to you), and those you have received/are currently receiving for the treatment of your NET. Blue text indicates significant differences between visitors to specialist centers versus non-specialist center visitors, $P < 0.05$.

Figure 8. Patient view on NET medical care.

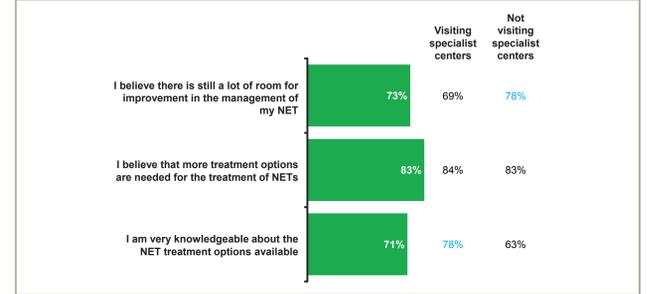


Base population: All respondents (N = 1928). Question: To what extent do you agree or disagree with the following statements? Top 2 box scores shown (Somewhat agree/Strongly agree). Blue text indicates significant differences between visitors to specialist centers versus non-specialist center visitors, $P < 0.05$.

Patient views regarding NETs

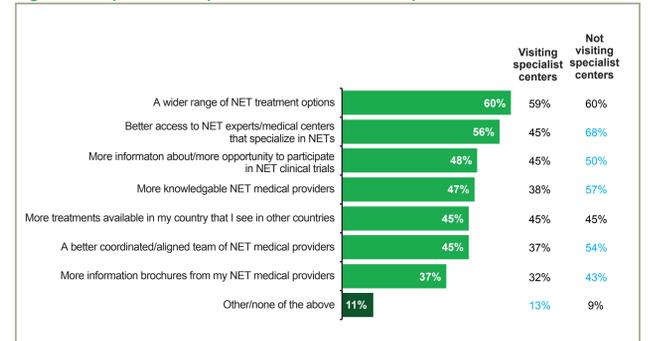
- Patients who visited NET specialist centers had more positive feelings regarding NETs than non-specialist center visitors
 - Less frustrated: 26% versus 30%
 - Less isolated: 15% versus 22%
 - More optimistic: 24% versus 18%
 - More motivated: 20% versus 15%
- Specialist center visitors felt more knowledgeable than non-specialist center visitors about NETs (78% vs 63%; Figure 9) and were less likely to feel confused regarding NET management (35% vs 43%). In addition, fewer believed that there is still a lot of room for improvement in NET management (69% vs 78%; Figure 9), including better access to NET experts, more information/opportunities to participate in clinical trials, more knowledgeable NET medical providers, and a better coordinated NET medical team (Figure 10)

Figure 9. Patient feelings regarding NET medical management.



Base population: All respondents (N = 1928). Question: To what extent do you agree or disagree with the following statements? Top 2 box scores shown (Somewhat agree/Strongly agree). Blue text indicates significant differences between visitors to specialist centers versus non-specialist center visitors, $P < 0.05$.

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



Base population: All respondents (N = 1928). Question: Which of the following would help with the ongoing management of your NET? Blue text indicates significant differences between visitors to specialist centers versus non-specialist center visitors, $P < 0.05$.

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 first large, global survey of patients with NETs demonstrated the benefits of an MDT approach, including improved satisfaction with care and interactions with HCPs, and a more positive, informed perspective regarding NETs
 - While patients typically traveled significantly greater distances to visit NET specialist centers, they had an overall better experience, including the range of topics discussed with their physicians, number of medical tests conducted per year, quality of and access to treatments, and access to informed HCPs
- Despite improvements seen with MDT care at NET specialist centers, the survey also highlighted remaining unmet needs in the management of NETs
 - 40% of patients visiting NET specialist centers did not feel their HCPs worked as a well-coordinated team, demonstrating room for improvement in medical team interactions
 - 34% of NET specialist center visitors did not rate the quality of NET-related treatments as good/very good, and many patients did not have access to NET treatments, demonstrating the need for improvements in and patient access to NET treatments
 - 69% believed there was a lot of room for improvement in the management of NETs
 - 84% believed more NET treatment options are needed

REFERENCES

- Oberg KE. *Ann Oncol*. 2010;21(suppl 7):vii72-vii80.
- Boudreaux JP, et al. *Pancreas*. 2010;39(6):753-766.
- Vinik AI, et al. *Pancreas*. 2010;39(6):713-734.
- Singh S, et al. *J Oncol Pract*. 2010;6(6):e11-e16.
- Metz DC, et al. *Curr Opin Endocrinol Diabetes Obes*. 2012;19(4):306-313.
- Jensen RT, et al. *Neuroendocrinology*. 2012;95:98-119.
- Anthony LB, et al. *Pancreas*. 2010;39(6):767-774.

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, Carcinor; Singapore, 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



Scan this QR code

Text Message (SMS)

Text: Q014e9
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=014e9>

Standard data or message rates may apply.