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

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BACKGROUND

- Neuroendocrine tumors (NET) are rare neoplasms arising from neuroendocrine cells throughout the body[1, 2]
- Despite a continuously increasing incidence,[3, 4] NETs remain poorly understood among the general public and many in the medical community
  - Only a few small (N <20) qualitative studies on the NET patient experience have been published[5, 6]
  - Data regarding the impact of NETs on patients' lives, including differences by tumor location, are inconsistently available around the world and have not been examined in the global population
- The chronic nature and the unpredictable disease course of NETs challenge the coping mechanisms of patients and caregivers[5]
  - Studies in Norway and the United States have shown health care–related quality of life scores to be significantly lower in patients with NETs compared with the general population[7,8]
    - In particular, NET-related symptoms, including diarrhea and flushing, were associated with reduced quality of life[7]
- 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 global data on the patient experience and disease burden by NET type

AIM

- To raise awareness of the burden of NETs on patients' daily lives by tumor location

METHODS

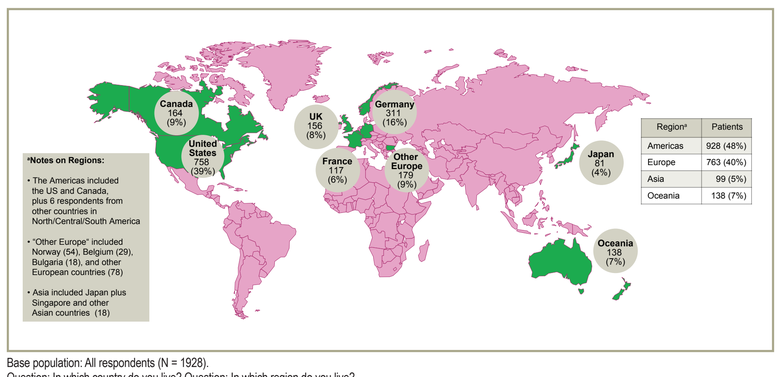
- From February through May 2014, patients with NETs participated in a 25-minute anonymous survey that captured the NET patient experience, including disease burden by NET type
  - With the exception of certain demographic information, survey questions were close-ended; participants were provided options 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 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 health care providers (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.



Region[a]	Patients
Americas	928 (48%)
Europe	763 (40%)
Asia	99 (5%)
Oceania	138 (7%)

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

- The 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 with GI NETs (63%), lung NETs (54%), or pancreatic NETs (pNETs) (59%) had grade (G) 1 or G2 disease (**Table**)
  - Lung NETs were more likely to be high grade (G3) (9%) compared with pNETs (5%) and GI NETs (4%)
  - Tumor grade was unknown for a third of patients across all 3 primary NET subtypes (physician did not give a grade; physician does not give grade or describe/discuss; patient did not remember)
- Patients with GI NETs (55%) were more likely than those with lung NETs (32%) or pNETs (26%) to have functional tumors

Table. Patient-Reported Functional Status and Grade of NETs[a]

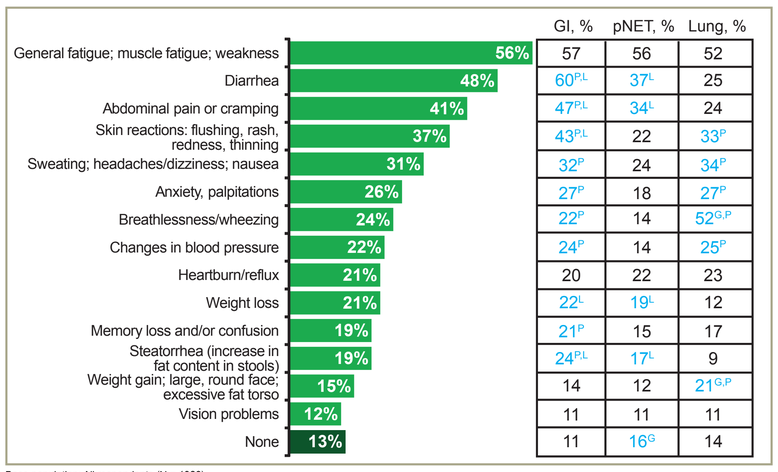
Tumor Type	Functional Status, %			Grade, %		
	Functional[b]	Nonfunctional[c]/ Asymptomatic[d]	Unknown[e]	G1[f]/G2[g]	G3[h]	Unknown[i]
GI NET (n = 1045)	55	27	18	63	4	32
pNET (n = 427)	26	57	18	59	5	36
Lung NET (n = 222)	32	40	28	54	9	37

Base population: All respondents (N = 1928).
Question: How, if at all, does your physician describe the functional status of your NET.
Question: Which of the following, if any, does your physician currently use to describe the grade of your NET.
[a]Some percentages sum to 99% or 101% due to rounding.
[b]Produces symptoms caused by the secretions of hormones (eg, flushing, diarrhea, wheezing, cramping).
[c]Do not secrete hormones; however, they may elicit symptoms caused by the tumor's growth (eg, pain, intestinal blockage, bleeding).
[d]Experience no symptoms.
[e]Physician does not describe/discuss; I don't remember.
[f]NETs are relatively slow growing; Ki-67 index <2%.
[g]NETs have a less predictable, moderately aggressive course; Ki-67 index 3%-20%.
[h]NETs can be highly aggressive; Ki-67 index >20%.
[i]Physician did not give my NET a grade/describe/discuss; I don't remember.
Blue text indicates significant differences between comparison groups, P <0.05.

Impact of NETs on patients' lives

- Patients with GI NETs (73%) were significantly more likely than those with lung NETs (66%) but not pNETs (70%) to report experiencing a large/moderate negative impact on daily life
- Patients reported experiencing a wide spectrum of symptoms (**Figure 2**), often related to NET location, many of which occurred on a daily or weekly basis (**Figure 3**)
  - Breathlessness/wheezing was reported more often with lung NETs (52%) than with GI NETs (22%) or pNETs (14%)
  - Diarrhea was reported more often with GI NETs (60%) than pNETs (37%) or lung NETs (25%)
- Patients also experienced various conditions as a result of their NETs, mostly GI related, with a similar incidence across all tumor types (**Figure 4**)

Figure 2. NET-related symptoms reported by patients.



		GI, %	pNET, %	Lung, %
General fatigue; muscle fatigue; weakness	56%	57	56	52
Diarrhea	48%	60[P,L]	37[L]	25
Abdominal pain or cramping	41%	47[P,L]	34[L]	24
Skin reactions: flushing, rash, redness, thinning	37%	43[P,L]	22	33[P]
Sweating; headaches/dizziness; nausea	31%	32[P]	24	34[P]
Anxiety, palpitations	26%	27[P]	18	27[P]
Breathlessness/wheezing	24%	22[P]	14	52[G,P]
Changes in blood pressure	22%	24[P]	14	25[P]
Heartburn/reflux	21%	20	22	23
Weight loss	21%	22[L]	19[L]	12
Memory loss and/or confusion	19%	21[P]	15	17
Steatorrhea (increase in fat content in stools)	19%	24[P,L]	17[L]	9
Weight gain; large, round face; excessive fat torso	15%	14	12	21[G,P]
Vision problems	12%	11	11	11
None	13%	11	16[G]	14

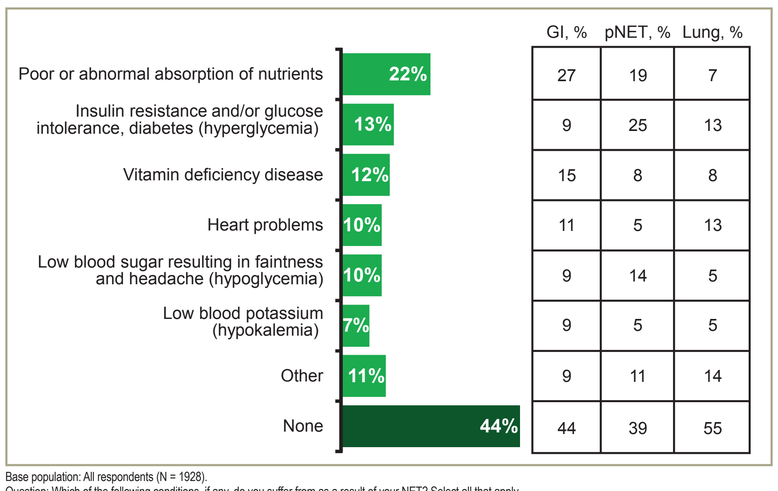
Base population: All respondents (N = 1928).
Question: Which of the following symptoms, if any, do you suffer from as a result of your NET? Select all that apply.
Blue text indicates significant differences between comparison groups, P <0.05. Superscripted letters appearing next to a given value indicate differences between that NET subtype compared with the other NET subtypes (GI NET = G, pNET = P, Lung NET = L).

Figure 3. Frequency of NET-related symptoms reported by patients.

		Daily/ constantly,%	2x/week, %	Weekly, %
General fatigue, muscle fatigue, weakness	(n = 1088)	72	14	8
Diarrhea	(n = 924)	41	28	12
Skin reactions: flushing, rash, redness, thinning	(n = 706)	46	24	9
Abdominal pain or cramping	(n = 783)	41	29	12
Sweating, headache/dizziness, nausea	(n = 589)	41	27	14
Anxiety, palpitations	(n = 492)	35	32	13
Breathlessness/wheezing	(n = 471)	52	24	11
Changes in blood pressure	(n = 428)	45	16	13
Memory loss and/or confusion	(n = 373)	53	27	10
Heartburn/reflux	(n = 401)	46	25	13
Steatorrhea (increase in fat content in stools)	(n = 368)	46	28	15
Weight loss	(n = 399)	38	4	9
Weight gain; large, round face; excessive fat torso	(n = 289)	75	2	4
Vision problems	(n = 226)	67	15	5
Osteoporosis	(n = 136)	82	2	1
Rectal bleeding	(n = 96)	15	17	14
Jaundice	(n = 27)	30	0	7
Other	(n = 125)	54	11	4

Base population: All respondents (n = varies).
Question: How frequently do you suffer from each of the following symptoms as a result of your NET?

Figure 4. Conditions occurring as a result of NETs.



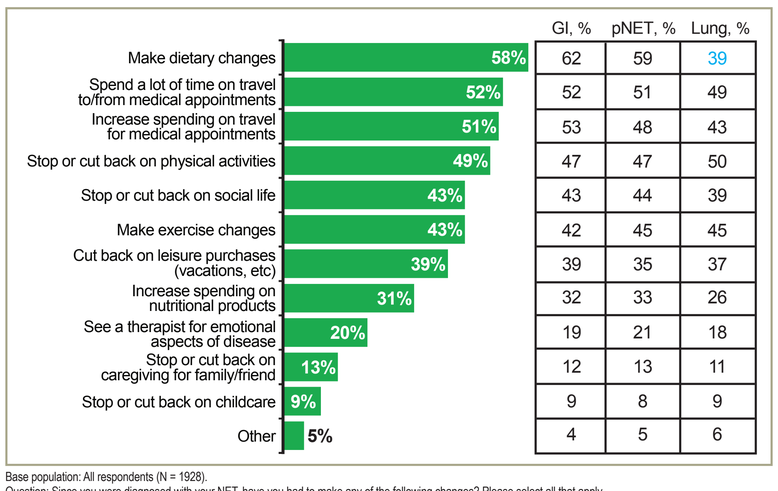
		GI, %	pNET, %	Lung, %
Poor or abnormal absorption of nutrients	22%	27	19	7
Insulin resistance and/or glucose intolerance, diabetes (hyperglycemia)	13%	9	25	13
Vitamin deficiency disease	12%	15	8	8
Heart problems	10%	11	5	13
Low blood sugar resulting in faintness and headache (hypoglycemia)	10%	9	14	5
Low blood potassium (hypokalemia)	7%	9	5	5
Other	11%	9	11	14
None	44%	44	39	55

Base population: All respondents (N = 1928).
Question: Which of the following conditions, if any, do you suffer from as a result of your NET? Select all that apply.

Impact of NETs on daily life and work life

- NETs impacted various aspects of patients' daily lives (**Figure 5**)
  - Patients with GI NETs (62%) or pNETs (59%) more often made dietary changes than those with lung NETs (39%)
- NETs also impacted patients' work
  - Fewer patients with GI NETs (3%) were likely to switch to a new job because of their disease than patients with lung NETs (8%) or pNETs (9%) (**Figure 6**)
  - Of respondents who were not currently employed or not able to work because of medical disability (n = 440), more patients with GI NETs (84%) or pNETs (83%) reported having to stop working because of NETs than patients with lung NETs (69%)

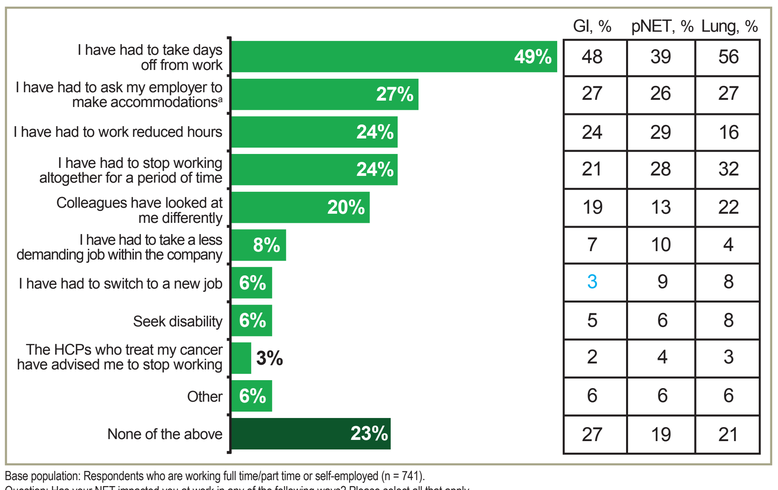
Figure 5. Impact of NETs on patients' daily lives.



		GI, %	pNET, %	Lung, %
Make dietary changes	58%	62	59	39
Spend a lot of time on travel to/from medical appointments	52%	52	51	49
Increase spending on travel for medical appointments	51%	53	48	43
Stop or cut back on physical activities	49%	47	47	50
Stop or cut back on social life	43%	43	44	39
Make exercise changes	43%	42	45	45
Cut back on leisure purchases (vacations, etc)	39%	39	35	37
Increase spending on nutritional products	31%	32	33	26
See a therapist for emotional aspects of disease	20%	19	21	18
Stop or cut back on caregiving for family/friend	13%	12	13	11
Stop or cut back on childcare	9%	9	8	9
Other	5%	4	5	6

Base population: All respondents (N = 1928).
Question: Since you were diagnosed with your NET, have you had to make any of the following changes? Please select all that apply.
Blue text indicates significant differences between comparison groups, P <0.05.

Figure 6. Impact of NETs on patients' work.



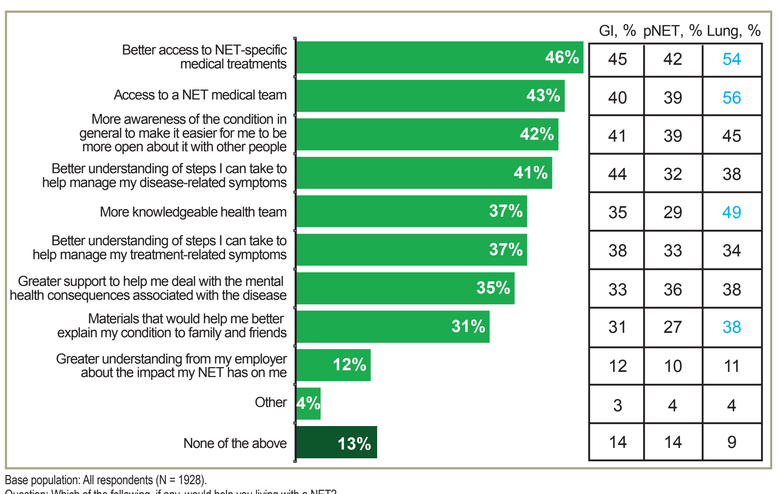
		GI, %	pNET, %	Lung, %
I have had to take days off from work	49%	48	39	56
I have had to ask my employer to make accommodations[a]	27%	27	26	27
I have had to work reduced hours	24%	24	29	16
I have had to stop working altogether for a period of time	24%	21	28	32
Colleagues have looked at me differently	20%	19	13	22
I have had to take a less demanding job within the company	8%	7	10	4
I have had to switch to a new job	6%	3	9	8
Seek disability	6%	5	6	8
The HCPs who treat my cancer have advised me to stop working	3%	2	4	3
Other	6%	6	6	6
None of the above	23%	27	19	21

Base population: Respondents who are working full time/part time or self-employed (n = 741).
Question: Has your NET impacted you at work in any of the following ways? Please select all that apply.
[a]Eg, flexible work schedule, work from home, adaptive devices, opportunities for rest.
Blue text indicates significant differences between comparison groups, P <0.05.

Key improvements patients believe would help them live better with NETs

- Patients suggested various improvements they felt would help them live better with NETs (**Figure 7**)
  - Patients with lung NETs were more likely to desire better access to NET–specific treatments, a NET medical team, a more knowledgeable medical team, and materials that help explain NETs to family and friends than patients with other NET types
    - Across tumor types, patients who visited a NET specialist center at least once/year appeared to be less in need of all these factors than non–specialist center visitors

Figure 7. Improvements patients believed would help them live better with NETs.



		GI, %	pNET, %	Lung, %
Better access to NET-specific medical treatments	46%	45	42	54
Access to a NET medical team	43%	40	39	56
More awareness of the condition in general to make it easier for me to be more open about it with other people	42%	41	39	45
Better understanding of steps I can take to help manage my disease-related symptoms	41%	44	32	38
More knowledgeable health team	37%	35	29	49
Better understanding of steps I can take to help manage my treatment-related symptoms	37%	38	33	34
Greater support to help me deal with the mental health consequences associated with the disease	35%	33	36	38
Materials that would help me better explain my condition to family and friends	31%	31	27	38
Greater understanding from my employer about the impact my NET has on me	12%	12	10	11
Other	4%	3	4	4
None of the above	13%	14	14	9

Base population: All respondents (N = 1928).
Question: Which of the following, if any, would help you living with a NET?
Blue text indicates significant differences between comparison groups, 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 NET patient survey demonstrated the considerable impact NETs have on patients' daily lives and work-related activities, and identified select differences among tumor types
  - Patients experience a wide spectrum of NET-related symptoms and conditions, many on a daily basis, that are often related to tumor location
  - NETs have a considerable impact on patients' personal and work lives
  - Patients with GI NETs were more likely to report experiencing a large/moderate negative impact on daily life than patients with lung NETs
  - Patients with GI NETs or pNETs more often made dietary changes than those with lung NETs
  - More patients with GI NETs or pNETs reported having to stop working due to NETs than patients with lung NETs
- This survey identified several improvements to help enhance the care of patients living with NETs, including increased access to NET-specific medical treatments and teams
  - Patients with lung NETs were more likely than those with pNETs or GI NETs to desire better access to NET-specific treatments/medical team, a more knowledgeable medical team, and informational materials that help explain NETs to family and friends

REFERENCES

1. Oberg KE. *Ann Oncol*. 2010;21(suppl 7):vii72-vii80.
2. Vinik AI, et al. *Pancreas*. 2010;39(6):713-734.
3. Yao JC, et al. *J Clin Oncol*. 2008;26(18):3063-3072.
4. Korse CM, et al. *Eur J Cancer*. 2013;49(8):1975-1983.
5. Feinberg Y, et al. *Eur J Oncol Nurs*. 2013;17(5):541-545.
6. Griffiths J, et al. *Eur J Oncol Nurs*. 2007;11(5):434-441.
7. Beaumont JL, et al. *Pancreas*. 2010;39(2):271 (Abstract).
8. Haugland T, et al. *Qual Life Res*. 2009;18(6):719-726.

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