Lung Neuroendocrine Tumor (NET) US Patient-Reported 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
NETs are rare, heterogeneous group of neoplasms whose incidence has recently risen over the past few decades. NETs originating in the lung (lUNG) are classified in 1 of 4 subtypes: small cell lung cancer (SCLC), large cell neuroendocrine carcinoma (LCNEC), atypical carcinoid (AC), and typical carcinoid (TC). Lung NET prognosis varies by tumor subtype and corresponding degree of malignancy – TC is low grade, AC is intermediate grade, and SCLC and LCNEC are poorly differentiated and highly aggressive. However, TC and AC currently lack well-developed treatment guidelines. A large proportion of patients with NETs are asymptomatic at diagnosis, and this contributes to treatment delays and reduced survival. To date, limited data have been published on the experience of patients living with NETs, nor have there been comprehensive surveys of the burden faced by patients with lung NETs. INCA is a network of 18 independent charitable organizations and patient groups from 15 countries around the world. Novartis Pharmaceuticals Corporation collaborated with INCA so that the global survey to gather NET patient experience from multiple countries, with the goals of

AIM
• To describe the burden of lung NETs through patient-reported experiences.

METHODS
• Data were analyzed at global, regional, and country levels; here, we present results from multiple countries, with the goals of

RESULTS
Statistical differences between comparisons were significant at the 95% confidence level (P < 0.05) for all statements within the text.

DIAGNOSIS AND MANAGEMENT OF LUNG NETS
• For approximately one-third of the patients surveyed (31%), >5 years elapsed from symptom onset to a diagnosis of lung NET (Figure 3).
  • Almost half of all patients (50%) were diagnosed with other conditions prior to lung NET (median, 5 years before NET diagnosis; Figure 3).
  • The majority of patients had not made a NET specialist center (64%)
  • Of those who had, only 12% were diagnosed more than 1 year before.

Figure 3. Diagnosis before NET diagnosis.

Figure 4. Impact of NETs on quality of life and work life.

Response rates vary by survey question. The majority of questions were open-ended and allowed patients to provide responses that were not provided in the list of possible responses. This could result in over-representation of responses from patients with NETs. Patients with NETs may not have fully experienced the full impact of NETs on their quality of life, employment, and health care utilization.

Figure 5. Impact of NETs on work life.

Key improvements patients believe would help them live better with NETs

Patient Perception of NET Management and Treatment
• Patient-reported areas for improvement (53% of patients) included: inability to receive answers to questions (53% of patients), difficulty in finding doctors (33% compared with outpatients), and difficulty finding information about NETs (26%).

Figure 7. Patient perception of NET management.

LIMITATIONS
• The large NET patient survey had several important limitations that may have impacted results.

REFERENCES

ACKNOWLEDGMENTS
• This project was supported by the American Lung Association in the United States who coordinated this project. The American Lung Association and CancerCare Management, Inc. provided unrestricted educational support. Medical editorial assistance for the posterior was provided by the Astrogenic Havoces. Funding was provided by Novartis Pharmaceuticals Corporation.

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Patient Experience of Lung Neuroendocrine Tumor (NET) Treatment – Results From the First Global NET Patient Survey – A Collaboration between the International Neuroendocrine Cancer Alliance (INCA) and Novartis

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Lung Neuroendocrine Tumor (NET) US Patient-Reported 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

NETs are a heterogeneous group of neoplasms whose incidence has recently risen over the past two decades. NETs originating in the lung (lung NETs) are classified in 1 of 4 categories: small cell lung cancer (SCLC), atypical carcinoid (AC), large cell neuroendocrine carcinoma (LCNEC), and typical carcinoid (TC). Lung NETs are characterized by neuroendocrine features and typically have a better prognosis than non-NET lung cancers. The diagnostic and treatment paradigms for lung NETs are different from other NETs.

A large proportion of patients with lung NETs are asymptomatic at diagnosis, and this contributes to their late detection and reduced survival. To date, limited data have been published on the experience of patients living with NETs.4–11 Extensive use of online social media sources through local/regional advocacy groups and health care providers (HCPs) have advised me to stop working. Of those who had, only 13% were diagnosed there – 8% in a hospital, 24% in a doctor’s office, 12% in an urgent care clinic, 2% in an emergency department, and 1% in another setting. Of those who were still working at the time of the survey, 31% reported having to stop working due to NET-related reasons (Figure 4).

RESULTS

– Of patients with lung NETs who were still working at the time of the survey, 31% reported having to stop working due to NET-related reasons (Figure 4).

Figure 2. Time between first symptom onset and diagnosis.

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BACKGROUND

- NETs are a heterogeneous group of neoplasms whose incidence has recently risen over the past few decades.
- NETs originating in the lung (lung NETs) are classified in 1 of 11 categories: small cell carcinoma (SCLC; 20%), large cell neuroendocrine carcinoma (LCNEC; 3%), atypical carcinoid (AC; 0.2%), and typical carcinoid (TC; 2%).
- Lung NET diagnostic criteria varies by tumor subtype and corresponding degree of malignancy.
- The American Joint Committee on Cancer (AJCC) TNM staging system categorizes tumors as stage I (C0), stage II (C1), stage III (C2), and stage IV (C3).
- A large proportion of patients with lung NETs are asymptomatic at diagnosis, and this contributes to treatment delays and reduced survival.
- To date, limited data have been published on the experience of patients living with NETs; most studies have focused on the burden in patients with lung NETs.
- INCA is a network of 10 independent charitable organizations and patient groups from 20 countries, with the goals of supporting patients, increasing public awareness, and providing education about NETs.

AIM

- To describe the burden of lung NETs through patient-reported experiences.

METHODS

- Data was collected from January 2014 through May 2014, with patients with lung NETs participating in a 26-region anonymous survey that captured the NET patient experience, including clinical disease, medical resource use, and access to care.
- Patients were recruited via social media outlets, events, and social media channels.
- The survey included a total of 1702 respondents from 20 countries.
- The majority of respondents were male (67%), aged 30–69 years (52%), Caucasian (75%), and high school educated or less (55%).
- Of the respondents, 15% had lung NETs (n = 112).

RESULTS

- Patients with lung NETs (n = 112) were more likely to have had a previous cancer diagnosis (81%, 95% CI 68–93) compared with all respondents (58%, 95% CI 45–71).
- Patients with lung NETs were more likely to have reported nonfinancial barriers (43%, 95% CI 26–61) and financial barriers (37%, 95% CI 19–55) to care compared with all respondents (31%, 95% CI 24–38 and 23%, 95% CI 14–32, respectively).
- Patients with lung NETs were more likely to have had the diagnosis of their NET made in the US (55%, 95% CI 37–73) compared with all respondents (23%, 95% CI 13–36).
- Of patients with lung NETs who were still working at the time of the survey, 31% reported having to stop working due to their NET.
- The top three NICE clinical practice guidelines followed were those for neuroendocrine tumors, gastroenterological tumors, and urological tumors.

Diagnosis and Management of Lung NETs

- For approximately 80% of the patients surveyed (31%), >5 years elapsed from symptom onset to diagnosis of lung NET (Figure 1).
- Almost half of all patients (50%) were diagnosed with other conditions prior to their lung NET diagnosis (20% of patients reported a false-negative result on their chest X-ray).
- The majority of patients had not made a NET specialist center (64%).
- Only 35% of patients with lung NETs had been referred to a NET specialist (nonsignificant).
- Patients with lung NETs were more likely than those with other NET types to have negative feelings regarding various aspects of their care.

Key Improvements Patients Believe Would Help Them Live Better with NETs

- Overall, patients with lung NETs had more negative feelings regarding health care provider behavior and quality of care compared with the overall NET population (Figure 6).
- Lung NET patients were more likely to desire better access to NET-specific medical treatments (58%, 95% CI 44–72) and a more knowledgeable health care team (52%).
- When asked what could have helped the patient have a better experience following diagnosis, 10% of lung NET patients believed they had been referred too late.

Figure 5. Impact of NETs on work life.

- The top three NICE clinical practice guidelines followed were those for neuroendocrine tumors, gastroenterological tumors, and urological tumors.

LIMITATIONS

- The large NET patient survey had several important limitations that may have impacted results.
- Patients with lung NETs were more likely than those with other NET types to have negative feelings regarding various aspects of their care.
- A number of factors, including access to care, have a significant impact on patients with lung NETs.

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ACKNOWLEDGMENTS

- The authors would like to thank the patients who participated in this survey and the patient advocacy organizations in the United States who contributed to this project. The Garden Foundation and Cancer Care for Excellence for their support.

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Lung Neuroendocrine Tumor (NET) US Patient-Reported Experience: Results From the First Global NET Patient Survey – A Collaboration between The International Neuroendocrine Cancer Alliance (INCA) and Novartis

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**Limited data have been published on the experience of patients living with NETs.**

**Purpose:** The aim of this survey was to describe the experience of patients living with NETs and identify unmet needs that can be addressed. This survey did not use standardized, validated quality-of-life assessments.

**Methods:** This survey was conducted online from May 2014 through April 2015. Patients with lung NETs participated in a 25-minute anonymous survey that captured the NET patient experience, including disease burden, medical resource use, and access to care. Patients with NETs were recruited via use of flyers, Web site postings, e-mails, and social media sources through local/regional advocacy groups and health care providers (HCPs) to reach patients without Internet access. Diagnosis and management of Lung NETs included extensive use of online social media sources through local/regional advocacy groups and health care providers (HCPs) to reach patients without Internet access. Diagnosis and management of Lung NETs included extensive use of online social media sources through local/regional advocacy groups and health care providers (HCPs) to reach patients without Internet access. Diagnosis and management of Lung NETs included extensive use of online social media sources through local/regional advocacy groups and health care providers (HCPs) to reach patients without Internet access. Diagnosis and management of Lung NETs included extensive use of online social media sources through local/regional advocacy groups and health care providers (HCPs) to reach patients without Internet access.

**Results:** Of 1644 patients who participated in the survey, 112 patients had lung NETs (6.8%) and 758 patients had lung NETs (46.5%). Patients with lung NETs were more likely to be past smoker (70% vs. 63%) and to have never had children (36% vs. 47%) compared with patients with other NET types. Patients with lung NETs were more likely to be past smoker (70% vs. 63%) and to have never had children (36% vs. 47%) compared with patients with other NET types. Patients with lung NETs were more likely to be past smoker (70% vs. 63%) and to have never had children (36% vs. 47%) compared with patients with other NET types. Patients with lung NETs were more likely to be past smoker (70% vs. 63%) and to have never had children (36% vs. 47%) compared with patients with other NET types.

**Key Improvements Patients Believe Would Help Them Live Better with NETs:**

- Overall, patients with lung NETs had more negative feelings regarding health care provider attitudes toward patients, disease-related uncertainty, and the impact of diagnosis as compared with other NET types.

- Patients with lung NETs were more likely to desire better access to NET experts (51%), reduced health care-related financial strain (50%), and more knowledgeable and responsive health care team (45%).

**Future Research:** Further research is needed to better understand the experience of patients living with NETs, focusing on cancer genetics, early detection, and support for patients and care providers.
**Lung Neuroendocrine Tumor (NET) US Patient-Reported Experience: Results From the First Global NET Patient Survey – A Collaboration Between the International Neuroendocrine Cancer Alliance (INCA) and Novartis**

**Edward Wolin,1 Maia Sissons,2 Grace Goldstein,3 John Leyden,4 Teodora Kolarova5**

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**BACKGROUND**

- NETs are a heterogeneous group of neoplasms whose incidence has recently risen over the past few decades.
- NETs originated in the lung (lung NETs) are classified into 1 of 4 subgroups: small cell lung cancer (SCLC), large cell neuroendocrine carcinoma (LCNEC), oat cell carcinoma (OC), and non-SCLC NETs (NSCLC).

**Aim**

- To describe the burden of lung NETs through patient-reported experiences.

**METHODS**

- In 2014, a 24-country anonymous survey was conducted to capture the NET patient experience, including disease burden, medical resource use, and access to care.
- Patients were recruited via use of flyers, Web site postings, e-mails, and social media.
- Patients were classified into 1 of 4 subgroups: Good News, moderate News, Bad News, and Worst News.
- Patients had the opportunity to participate in 1 of 4 surveys.
- Patients were recruited via use of flyers, Web site postings, e-mails, and social media.

**RESULTS**

- Of the 758 patients in the study, 15% of US patients had lung NETs (n = 112).
- Patients with lung NETs were more likely to be on the impression that their NET was curable (35% vs 18% and 16% for gastrointestinal [GI] and pancreatic [p]NETs, respectively) and that they had some control over their illness (39% of lung NET patients vs 35% for GI and pNET patients).

**Impact of NETs on Quality of Life and Work Life**

- 67% of patients with lung NETs experienced a moderate to large negative impact on their quality of life (Figure 4). The finding was similar with patients with GI NETs and pNETs (73% and 76%, respectively).

**Diagnosis and Management of Lung NETs**

- Of patients with lung NETs who were still waiting at the time of the survey, 31% reported having to stop working to deal with NET (Figure 5). This was higher than the overall patient population (20% of US NETs, 12% of GI NETs, and 11% of pNETs).

**DISCUSSION**

- This large NET patient survey had several important limitations that may have impacted the results.
- A patient-reported design was employed without independent verification, leading to potential recall bias.

**CONCLUSIONS**

- Findings from this large survey provide valuable information on the experience of patients with lung NETs.

**REFERENCES**


**ACKNOWLEDGMENTS**

- The authors would like to thank all patients who participated in this survey and all patient advocacy organizations in the United States who contributed to this project. The Cancer Genome Atlas and Cancer Genome Project.

**Key Improvements Patients Believe Would Help Them Live Better with NETs**

- Overall, patients with lung NETs had more negative feelings regarding health care providers' communication and quality of care received compared with the internets NET patient population (Figure 6).

**LIMITATIONS**

- The large NET patient survey had several important limitations that may have impacted the results.

**CONCLUSIONS**

- Findings from this large survey provide valuable information on the experience of patients with lung NETs.

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Key Improvements Patients Believe Would Help Them Live Better with NETs

- Overall, patients with lung NETs had more negative feelings regarding health care providers’ communication and quality of care discussions with the internist (78% of lung NET patients, 72% of internist patients).

- Lung NET patients were more likely to desire better access to NET experts (56%), more time spent on discussions of the NET (44%), and reduced symptom burden (34%).

- When asked what steps they would take if they had a better experience following a diagnosis, 24% of patients stated that they would consult a NET expert.

Figure 5: Improvements patients believed would help them live better with NETs.

Limitations

- The large NET patient survey had several important limitations that may have impacted results.

- A patient-identified design was employed without independent verification, leading to potential recall bias.

- This survey did not use standardised, validated quality-of-life assessments.

- Recruitment in the United States was conducted primarily through patient advocacy groups (36%) and online sources (32%), which may have resulted in over-representation of the lung NET patient population.

- Respondents were more likely to be highly engaged and involved cancer care-seekers, including female patients and those with a poorer prognosis.

Conclusions

- From the large-scale survey, we gathered valuable information on the experience of patients with lung NET.

- Almost one-third of patients were diagnosed >5 years after symptom presentation.

- The majority of patients experienced a large negative impact on their daily life and their work.

- A number of questions regarding improving the diagnosis and management of lung NET were identified, including better access to health care providers with NET expertise and9 improvements to better answer patient’s questions following diagnosis.

References


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