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: Lung NETs are rare, diverse tumors that are often asymptomatic, resulting in treatment delays and reduced survival. The burden of lung NETs on patients’ lives has not previously been described.

Methods: In 2014, 1928 NET patients from >12 countries including the United States (n=758) participated in a survey, conducted by Hall & Partners on behalf of INCA/Novartis, funded by Novartis, on the NET patient experience (comparisons significant at $P<0.05$).

Results: 15% of US patients had lung NETs, primarily nonfunctional/asymptomatic (53% of patients who knew status, n=79) and low grade (G1; 57%, n=70). 56% required ≥2 years for diagnosis; 49% were diagnosed with other conditions prior to NETs, most often asthma (56%) and pneumonia (35%). Most had not visited (64%)/been diagnosed (96%) at a NET specialist center. Lung NET patients were more likely to be
given the impression their cancer was curable (32%) and not something to worry about (40%) vs GI/pNETs (9%/14% and 23%/14%). However, similar to GI/pNETs (73%/74%), most lung NET patients (67%) experienced a moderate/large negative impact on quality of life and were more likely to temporarily stop working because of NETs (31%) vs GI/pNETs (12%/12%). Overall, patients with lung NETs had more negative feelings regarding health care provider expertise/knowledge and quality of care and were more likely to desire better access to NET experts (56%)/knowledgeable health care team (52%). Following diagnosis, fewer lung NET patients were satisfied they received answers to questions (43%) or sufficient information (33%) vs GI/pNETs (62%/59% and 48%/52%). 45% regarded quality of available treatments as poor/very poor (vs GI/pNETs [28%/33%]). Many (71%) expressed the need for more immediate access to NET specialists and transfers to NET centers of expertise (45%).

**Conclusion:** This large patient survey demonstrated the substantial burden of a lung NET diagnosis in the United States and identified areas for improvement.