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

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BACKGROUND
Neuroendocrine tumors (NETs) are a diverse group of malignancies that arise from neuroendocrine cells throughout the body. Symptoms of NETs may be nonspecific or absent and more advanced stages, 1 often leading to late diagnosis. 2
- NET-related symptoms may persist for a median of 9 years before a NET diagnosis 3
- Due to nonspecific 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 delayed diagnosis 4
- Delayed diagnosis has been associated with lower quality of care, including suboptimal treatment results, and may explain the high rate of complications observed in patients with NETs 5

METHODS
From February through May 2014, patients with NETs participated in a 25-minute web survey and then completed the NET patient experience, including perceived benefits of an NET care approach. 6
- With the exception of certain demographic information, survey questions were close-ended; participants were provided options from which to choose.
- Patients who visited a NET specialist center (n = 355) were more likely to visit a center than those who did not visit a NET specialist center (n = 1029).
- Creating individual patient experiences of long with NETs to understand the NET patient needs and values with NETs
- Highlighting differences and similarities between countries and regions to help improve NET care.

RESULTS
Demographics
A total of 2428 visits with NETs were recruited from 92 countries in the Americas, Asia, Europe, and Oceania (Figure 1).

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

Figure 2. NET specialist center visits.

Patient views regarding NETs
Patients visiting NET specialist centers had more positive feelings regarding NETs than non-specialist center visitors.

Table 1. Patient views regarding NETs.

Patient views regarding NETs

<table>
<thead>
<tr>
<th>Question</th>
<th>NET specialist center</th>
<th>Non-specialist center</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>More knowledgeable NET medical providers</td>
<td>87% (95% CI 84, 89)</td>
<td>79% (95% CI 76, 81)</td>
<td>&lt;0.05.&lt;0.05.&lt;0.05.&lt;0.05.</td>
</tr>
<tr>
<td>More informed about NET medical team</td>
<td>82% (95% CI 79, 85)</td>
<td>74% (95% CI 71, 76)</td>
<td>&lt;0.05.&lt;0.05.&lt;0.05.&lt;0.05.</td>
</tr>
<tr>
<td>More motivated</td>
<td>20% (95% CI 17, 23)</td>
<td>15% (95% CI 12, 18)</td>
<td>&lt;0.05.&lt;0.05.&lt;0.05.&lt;0.05.</td>
</tr>
<tr>
<td>More optimistic</td>
<td>24% (95% CI 21, 27)</td>
<td>18% (95% CI 15, 21)</td>
<td>&lt;0.05.&lt;0.05.&lt;0.05.&lt;0.05.</td>
</tr>
</tbody>
</table>

Medical treatments
Patients visiting NET specialist centers were more likely than non-specialist center visitors to rate their quality of NET-related treatments as “very good” (80% vs 69%) and “very well” (71% vs 61%) and were less likely to feel confused regarding treatment options (45% vs 57%) and treatment cost (48% vs 59%).

Table 2. Patients’ medical perceptions.

Medical treatments

<table>
<thead>
<tr>
<th>Treatment</th>
<th>NET specialist center</th>
<th>Non-specialist center</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very good</td>
<td>80% (95% CI 77, 83)</td>
<td>69% (95% CI 66, 71)</td>
<td>&lt;0.05.&lt;0.05.&lt;0.05.&lt;0.05.</td>
</tr>
<tr>
<td>Very well</td>
<td>71% (95% CI 68, 73)</td>
<td>61% (95% CI 58, 63)</td>
<td>&lt;0.05.&lt;0.05.&lt;0.05.&lt;0.05.</td>
</tr>
<tr>
<td>Confused</td>
<td>45% (95% CI 42, 48)</td>
<td>57% (95% CI 54, 59)</td>
<td>&lt;0.05.&lt;0.05.&lt;0.05.&lt;0.05.</td>
</tr>
<tr>
<td>Treatment cost</td>
<td>48% (95% CI 45, 50)</td>
<td>59% (95% CI 56, 61)</td>
<td>&lt;0.05.&lt;0.05.&lt;0.05.&lt;0.05.</td>
</tr>
</tbody>
</table>

ACKNOWLEDGMENTS
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