The NETwork! Registry analysis supports the WHO 2017 classification in the first NET specific survival analysis for a complete population

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Table 1. NET Epidemiology

<table>
<thead>
<tr>
<th>Author</th>
<th>Journal</th>
<th>Country</th>
<th>Time Period</th>
<th>Methodology</th>
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<tbody>
<tr>
<td>Hauso et al</td>
<td>Cancer</td>
<td>SEER, Norway Registry of Cancer</td>
<td>2008-2012</td>
<td>Generally, they do not measure NET specific survival.</td>
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<td>Hallet et al</td>
<td>Cancer</td>
<td>ICES, Canada</td>
<td>2015</td>
<td>We describe a study of every NET diagnosed in a whole country population, to overcome such limitations.</td>
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Background

- Descriptions of NET incidence and outcome use estimates of population denominator of variable quality.
- Generally, they do not measure NET specific survival.
- We describe a study of every NET diagnosed in a whole country population, to overcome such limitations.

Methods

- Data was collected from all patients diagnosed with a NET in New Zealand between 2008 and 2012, excluding pulmonary small cell carcinoma.
- Primary data source was the NZ Cancer Registry (73% of cases).
- Secondary data was obtained from searches of pathology records in every hospital in New Zealand.
- Clinical data was collated on each patient, including detailed pathology from individual medical records.
- Age adjusted incidence rates were calculated using Statistics New Zealand summary data for the total New Zealand population during each of the five years 2008-2012.
- Disease specific survival was ascertained by linking data to national records of date and cause of death.
- Reports of grade and differentiation were converted to WHO 2017 criteria where possible (42% and 88% respectively).

Results

- 1661 patients were diagnosed with NET, with age adjusted incidence increasing to 6.2 per 100,000 in 2012 (p=0.06).
- Disease specific survival for well differentiated NETs is significantly better than for poorly differentiated tumours (p < .0001, HR=6.7 95% CI 5.7-8.1).
- As expected, both overall and disease specific survival for combined low grade NETs (G1/2) was significantly better than high grade tumours (G3/NEC) (p < .0001). Interestingly, there was no difference between overall and disease specific survival in the low grade tumours.
- There was a significant difference between overall and disease specific survival shown in Figure 2 is accounted for by higher age at diagnosis rather than lower tumour grade.

Conclusions

To the best of our knowledge, this study describes the first analysis of NET incidence and outcome calculated using a whole national population as the denominator, and the first to report five year disease specific survival.

This highly accurate dataset supports extrapolating WHO 2017 pancreas guidelines to NETs from other sites. Although the majority of patients died of their NET, analysis of disease specific survival showed that this is not true in a proportion of older patients.

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