

1 **Update on Incidence, Prevalence Treatment and Survival of Patients with Small bowel**

2 **Neuroendocrine Neoplasms in The Netherlands**

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## **Abstract**

### Background

Small bowel neuroendocrine neoplasms (SB-NEN) are a rare cancer with relatively high survival rates compared to other cancers. Population-based studies are ideal to study this kind of indolent disease, as long time periods and large patient numbers are covered. The aim of this study is to provide an update on Dutch data by exploring trends in epidemiology, treatment and survival outcomes of patients with SB-NEN.

### Patients and methods

All patients with SB-NEN diagnosed between 2005 and 2015 were included from the Netherlands Cancer Registry (NCR). Corresponding histopathology reports were requested from The Nationwide Network and Registry of Histo- and Cytopathology in The Netherlands (PALGA). Age-adjusted incidence rates were calculated based on age groups according to Statistics Netherlands (CBS) using the direct standardization method. Descriptive statistics were used to present the distribution of data. Survival analyses were performed with the Kaplan-Meier method and the Cox proportional hazards model was used to identify factors associated with survival.

### Results

A total of 1451 patients were identified, of which 975 were included. The age-adjusted incidence rate of SB-NEN increased from 0.52 to 0.81 per 100.000 persons years between 2005 and 2015 and males were more represented than females (incidence of 0.93 versus 0.69 per 100.000 person years in 2015). Mean follow-up was 61 ( $\pm 38$ ) months, and all-cause mortality was 33%. Most patients had a grade 1 tumour (83%). Surgery was performed in 86%, of which 99% had undergone resection of the primary tumour. Administration of somatostatin analogues (SSAs) increased from 5 to 22% for stage III and from 27 to 63% for stage IV.

### Conclusions

This study showed an increase in the incidence of SB-NEN. A predominant role of surgery was found with an increased use of SSAs over time.

**Lay abstract**

Small bowel neuroendocrine tumors are a rare cancer with relatively high survival rates compared to other cancers. Studies using national data are ideal to study such rare disease, as long time periods are covered and large patient numbers are included. The aim of this study is to provide an update on Dutch data by exploring trends in epidemiology, treatment and survival outcomes of patients with small bowel neuroendocrine tumors. Data was collected from the Netherlands Cancer Registry, which contains all cases of cancer in The Netherlands. A total of 1451 patients were identified in the period 2005-2015, of which 975 were included in the analyses. Surgery was performed in 86% and the usage of somatostatin analogue injections increased from 27% to 63% for patients with distant metastases. As expected, the incidence also increased from 0.52 to 0.81 per 100.000 persons per year.