

## **Title**

Incidence and Prevalence of Neuroendocrine Tumours in England

## **Abstract**

### **Introduction**

Historically the incidence and prevalence of neuroendocrine tumours (NETs) has been difficult to establish due to issues with disease coding and data collection. Studies by Ellis *et al* in 2006 estimated the incidence of gastroenteropancreatic neuroendocrine tumours (GEP NETs) to be 1.3 per 100,000 per year (incidence hereafter given as cases per 100,000). However, the SEER USA data suggests a four-fold higher incidence, and prevalence of 35 per 100,000. This study aimed to identify the incidence and prevalence of NETs over a ten-year period utilising the Public Health England (PHE) population-based cancer registry.

### **Materials and methods**

Age-standardised incidence rates and prevalence from the 1st January 1995 to 31st March 2016 were calculated using data from the PHE National Cancer Registration and Analysis Service (NCRAS) database.

### **Results**

In 2015, the age-standardised incidence rate for NETs in England (excluding small and large cell neuroendocrine carcinomas, SCLC and LCNEC respectively) was 8.84, 8.37 in males [95% CI, 8.02-8.72] and 9.30 in females [95% CI, 8.91-9.71] and; rising from 3.9 in 2001, with an average yearly increase of 0.39 cases. The incidence of SCLC was 7.72 and LCNECs was 0.44. The cohort was 90.1% White, 2.6% Asian, 1.8% Black, 1.4% other and 4.0% ethnicity unknown.

The most common primary tumour sites were: 20.2% colorectal, 19.5% lung, 14.1% small intestinal, 9.6% pancreatic, 6.9% skin, and 5.3% stomach.

The stage breakdown was 23.3% stage I, 11.7% stage II, 14.2% stage III, 25.9% stage IV and 24.8% stage unknown in the 91.3% of the tumours with a histological confirmation from a primary, the remaining 8.7% were unknown primaries at diagnosis.

The prevalence was 19,268 (34.9 per 100 000), 8,743 males and 10,525 females.

## **Conclusion**

This study has clearly demonstrated that incidence of NETs in England is significantly higher than previously reported. The data demonstrate similar incidence and prevalence rates to those reported in the SEER database. Importantly, it highlights that colorectal and lung NETs are the most common primary sites.

**Keywords:** Neuroendocrine cancer, prevalence, incidence