



## Incidence and survival in neuroendocrine tumours and neuroendocrine carcinomas (NETs/NECs) in England, 2013-2014

### National Cancer Registration and Analysis Service Data Briefing

Neuroendocrine neoplasms have been identified at a national level for the first time, aided by the uniform registration in the ICD-O-3 coding system for cases diagnosed from 2013 onward.

All neoplasms diagnosed in England in 2013 & 2014 with a morphology code matching a code list [1] agreed by an expert clinical panel were included in the tumour cohort. 8,726 neoplasms were found [2], an (unstandardised) rate of approximately 8 per 100,000 persons.

Figure 1 shows the morphological and topological distribution of the neoplasms. Nearly half are NETs of low grade (G1 or G2), and the remainder are mostly NECs (small cell, large cell, or Not Otherwise Specified). There are also a smaller fraction of mixed adeno-neuroendocrine carcinomas, Merkel cell carcinomas and a few rarer morphologies. Lower GI neoplasms are predominantly (75%) NETs compared to upper GI (48%) and lung (36%), albeit that these figures exclude small cell carcinomas from the lung cohort.

The overall cohort has almost exactly a 50:50 male:female ratio, little obvious variation with geographic region or ethnicity, and a distribution with age similar to that of all the other malignant cancers combined. 20.2% of the patients were from the most affluent population quintile with 18.6% from the most deprived quintile ( $p=0.011$ ).

Figure 2 shows 1 year net survival for the patient group. NETs show high 1 year survival, even for more advanced stage of presentation. NECs and other subtypes show lower overall survival and a stronger dependence of survival on stage at diagnosis.

#### FIND OUT MORE:

[1] ICD-O-3 morphology codes used were: 8013, 8041, 8042, 8043, 8044, 8045, 8150, 8151, 8152, 8153, 8154, 8155, 8156, 8157, 8158, 8240, 8241, 8242, 8243, 8244, 8245, 8246, 8247, 8249, 8574, 9091

[2] By the judgement of the clinical panel this excludes 7,908 small cell lung cancers

[3] ICD-O-3 topography codes used were: C00-14, C30-32 Head & Neck; C15-16, C22-26 Upper GI; C17-C21 Lower GI; C33-C39 Lung; C44 Skin; C50 Breast; C51-58 Gynae; C60-68 Urological; C47, C69-C76, Other; C77, C80 and metastatic ("behaviour 6") tumours Unknown primary

#### Key messages

NETs/NECs have been identified at a national level for the first time.

Over 4,000 neuroendocrine neoplasms (8 per 100,000 persons) are diagnosed per year. They are found at a mixture of sites in the body with a varying relationship between stage at diagnosis and survival.

This cohort could be used to explore the patient pathway in more detail at a national level.

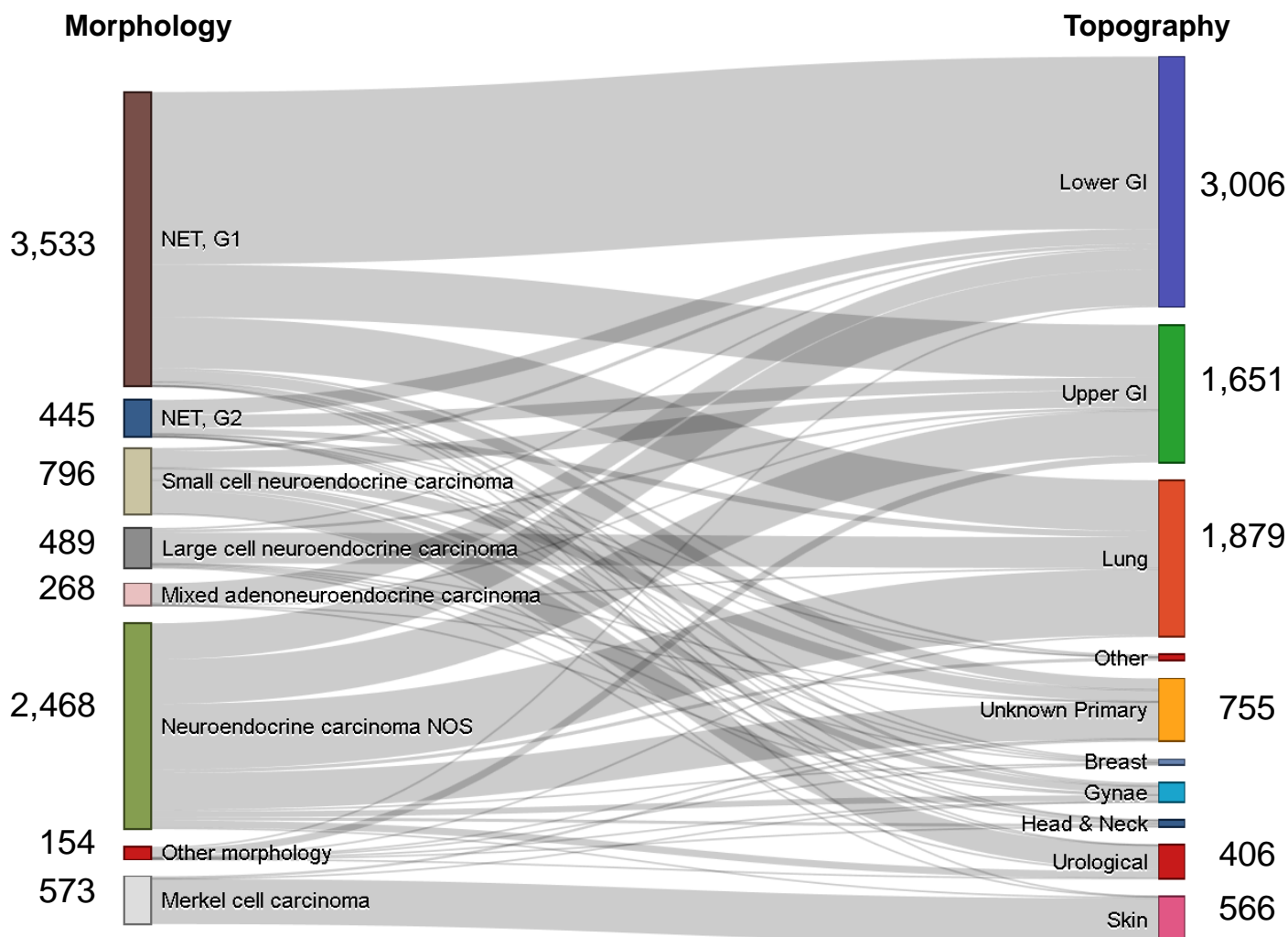


Figure 1: morphological and topological distribution of 8,726 neuroendocrine neoplasms diagnosed in England, 2013 and 2014

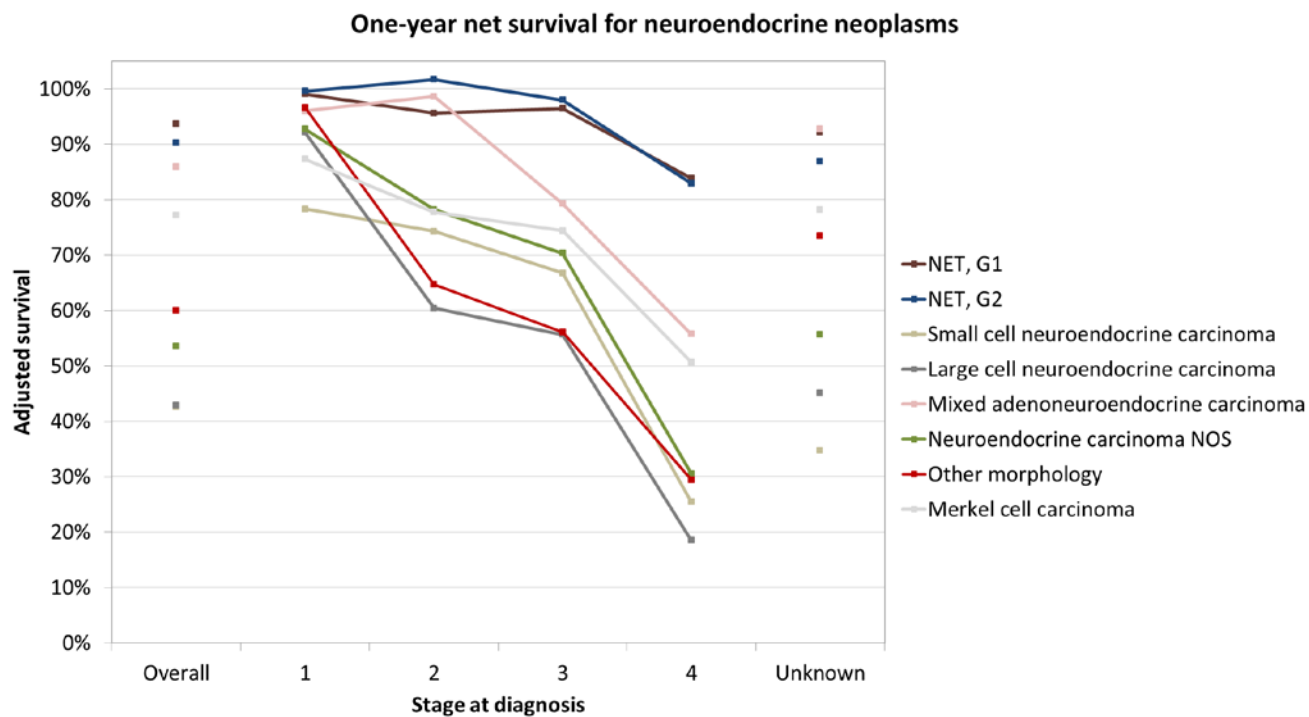


Figure 2: one year net survival for neuroendocrine neoplasms diagnosed in England, 2013-2014.