

Date: 01/08/2016

FREEDOM OF INFORMATION REQUEST FOI/012910 - Neuroendocrine Tumours

Assuming patients treated at DGFT between 1st June 2015 and 31st May 2016. Sourcing data for patients with Neuroendocrine Tumours from the trusts Somerset Cancer Register Database system, where patients are recorded as having one of the following SNOMed histology codes: 'M80133', 'M80413', 'M82463', 'M82473', 'M85743' [source: https://en.wikipedia.org/wiki/Neuroendocrine_tumor]. This data has been cross referenced with our data warehouse to find patients diagnosed with carcinoid syndrome or acromegaly.

1. In your trust, please provide the number of patients treated in the last 12 months who have been diagnosed [any diagnosis position] with neuroendocrine tumours

45 patients

2. Of these how many have carcinoid syndrome (E34.0)?

No patients

3. Of the patients with neuroendocrine tumours (NETs), how many received with the following treatments:

Somatuline Autogel (lanreotide) Somatuline LA (lanreotide) Sandostatin LAR (octreotide LAR) Octreotide Afinitor (everolimus) Sutent (sunitinib)

1 patient, broken down as

Somatuline Autogel (lanreotide) 0

Somatuline LA (lanreotide) 0

Sandostatin LAR (octreotide LAR) 1

Octreotide 0

Afinitor (everolimus) 0

Sutant (sunitinib) 0

4. Please provide the number of patients treated in the last 12 months who have been diagnosed [any diagnosis position] with acromegaly (ICD10 code E220 or ICD10 code D352), with the following treatments: Somatuline Autogel (lanreotide) Somatuline LA (lanreotide) Sandostatin LAR (octreotide LAR) Octreotide Somavert (pegvisomant) Signifor (pasireotide pamoate)

No patients

*To assist in sourcing the answer to my question specifically in respect of NETs, the below information may be of use. In relation to patients with neuroendocrine tumours, these tumours are typically identified from pathology analysis, but may be coded using various ICD10 codes. The following may be commonly used: C787 - Secondary malignant neoplasm of liver C786 - Secondary malignant neoplasm of retroperitoneum and peritoneum C772 - Secondary and unspecified malignant neoplasm of Intra-abdominal lymph nodes C780 – Secondary malignant neoplasm of the lung Z850 - Personal history of malignant neoplasm of digestive organs In any event, I am requesting information only in respect of those patients with neuroendocrine tumours who are being treated with the above treatments.