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Our ref: 3524

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Freedom of information request

I am writing in response to your request for information which has been handled under the Freedom of Information Act 2000 (FOIA).

Your questions and our response are below.

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

*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.

This specific information is not recorded. Neuroendocrine tumours are not coded any differently to other types of cancers on our system e.g. carcinoma etc. so impossible to pull this data as it would pull out all tumours from these sites irrespective of their histological type.