The NETwork! Registry: Preliminary data suggests increasing incidence in a national study of neuroendocrine cancer in New Zealand

Kate Parker[1], Esther Coats[1], Braden Woodhouse[1], Nicholas Knowlton[1], Cristin Print[1], Michael Findlay[1], Benjamin Lawrence[1]

[1] *University of Auckland, New Zealand on behalf of the NETwork! NZ collaboration*

Background The incidence, treatment and survival from neuroendocrine tumours (NETs) in New Zealand (NZ) has not previously been examined. Internationally, epidemiological descriptions of NETs are derived from institutional series or regional registries. In NZ there is a limited centralised record of NETs, as historically many were not recorded in the National Cancer Registry. We aimed to address this by compiling a national database of patients with NETs. We report initial data from a retrospective study, which includes every NET diagnosed in NZ over a 5-year period.

Aims

1. To identify all patients diagnosed with NETs in NZ. This was done in two groups; an in-depth picture of all NETs diagnosed in NZ between 2008 and 2012 (described in this poster) and a longer term view of NETs in the Auckland region diagnosed between 1995 and 2012.
2. To provide a definitive description of NET epidemiology and outcomes over this time period.

Methods Our primary data source was the New Zealand Cancer Registry searched using ICD-03 codes. Secondary data was obtained from searches of public and private pathology records in every District Health Board (n=20). Clinical data was collected from individual medical records. We collected information on 3334 patients (presentation, tumour characteristics, investigation, treatment and outcome). A team of research nurses and healthcare professionals entered data via a remote desktop using MS Access and a SQL database, secured using a double-password system (University network and database login), according to a centralized protocol and data dictionary.
Classification of NETs was defined as per WHO 2010 nomenclature. Neuroendocrine tumours in the analysis included gastroenteropancreatic (GEP) NETs, bronchopulmonary carcinoids and neuroendocrine carcinoma, extrapulmonary small cell carcinoma, large cell carcinoma, medullary thyroid carcinoma, Merkel cell carcinoma, paraganglioma and phaechromocytoma and NETs of other primary sites such as gynaecological and genitourinary. Pulmonary small cell carcinoma was excluded. Age adjusted incidence rates were calculated using Statistics New Zealand data for the NZ population during each of the five years 2008-2012 (1), adjusted against the WHO age distribution of a standard population (2001).

Figure 1. Age adjusted incidence of NETs

1736 patients were diagnosed with NET between 2008-2012. When adjusted for age, there is a 9% increase in incidence over the 5 year period. Age adjusted incidence is comparable to incidence found in studies overseas(2).

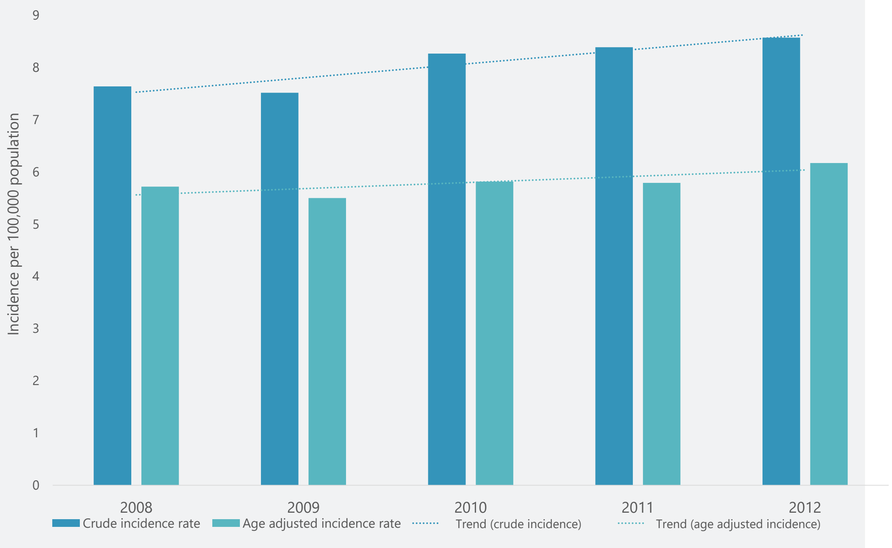


Figure 2. Spread of disease at diagnosis

A large proportion of patients (47%) had either lymph node or distant metastases diagnosed from radiological staging at diagnosis.

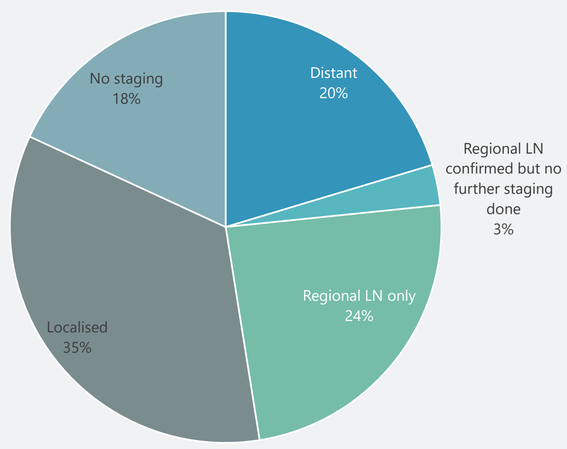


Figure 3. Primary site of NETs diagnosed 2008-2012

In total, gastroenteropancreatic NETs made up 49% of all NETs reported. Other common primary sites include lung (12%) and skin (11%). The primary site was unable to be identified in many cases (11%). The most common GEP NETs were jejunal / illeal (12%), appendical (11%) and pancreatic (7%).

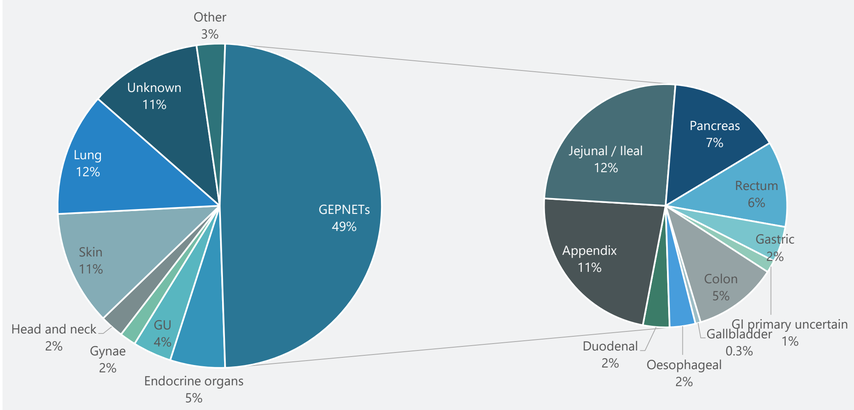


Figure 4. NET incidence by ethnicity

There appears to be a much lower rate of NETs in people of Asian ethnicity which warrants further investigation

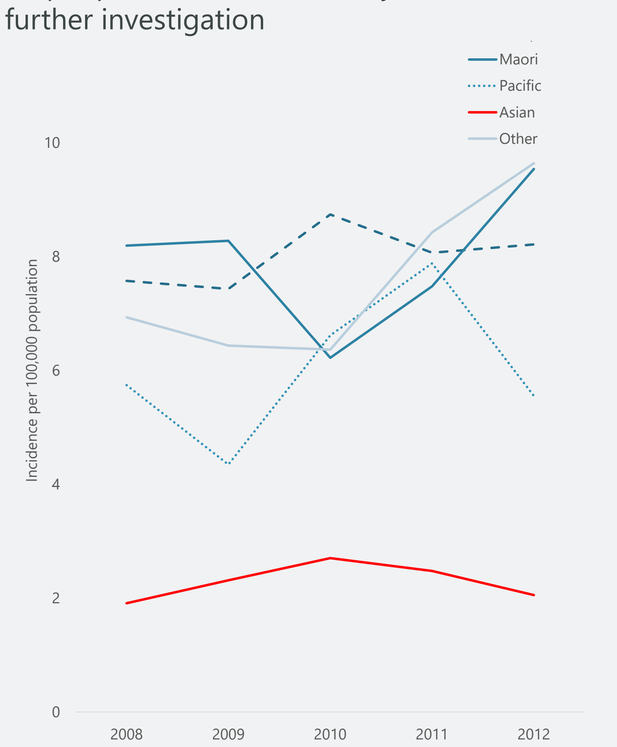


Figure 5. Age at diagnosis of NETs 2008-2012

The median age of diagnosis of NETs varies considerably with primary site. This suggests a diverse family of tumours with different aetiologies in different organ sites.

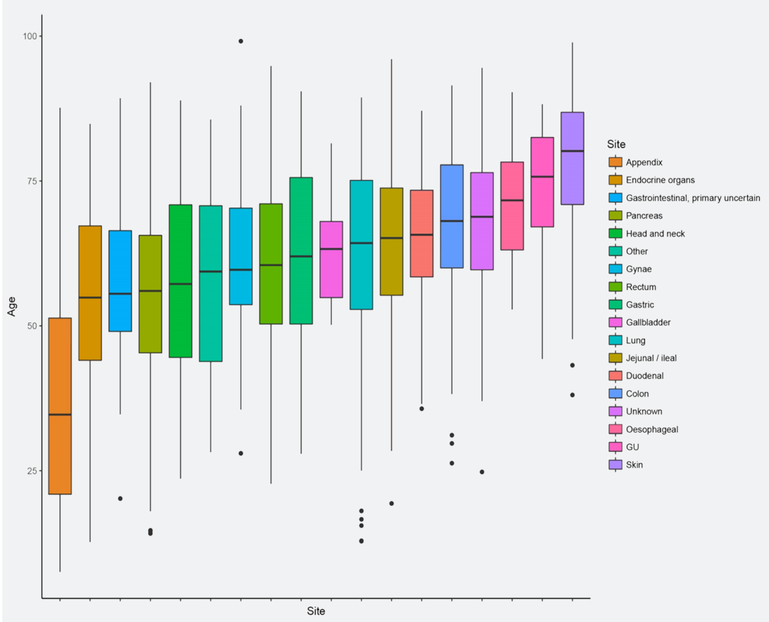
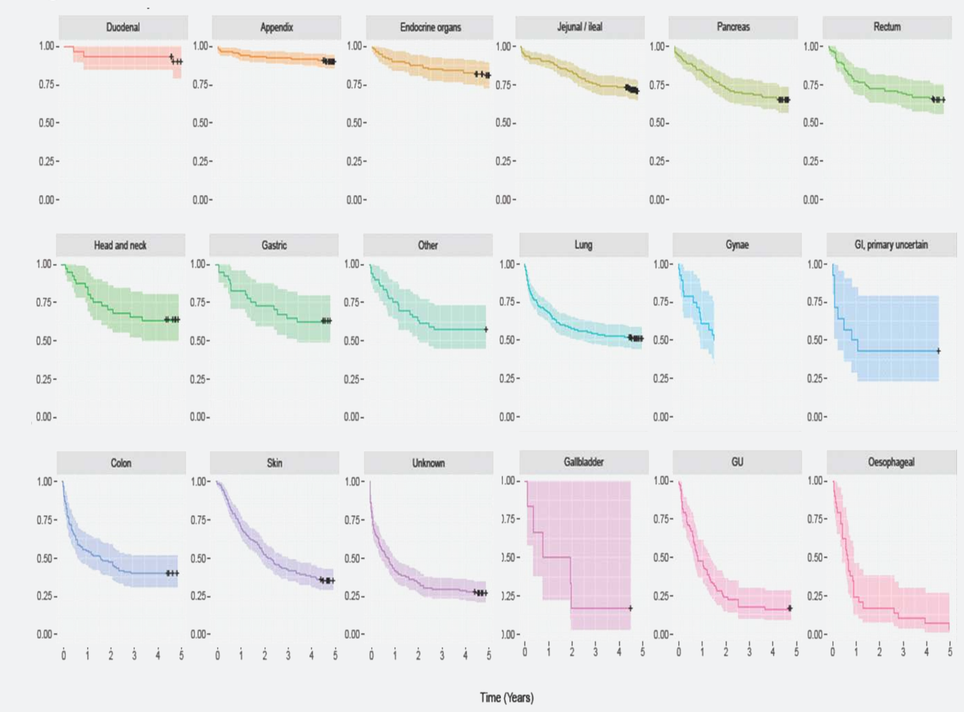


Figure 6. Survival of patients diagnosed with NETs 2008-2012

When reviewing mortality from all causes (not disease specific), the survival rates for patients with NETs vary considerably according to primary site of diagnosis. Overall, survival of NETs at 5 years post diagnosis is around 60%.



Conclusions

- The burden of neuroendocrine cancer is greater than previously perceived with a rising incidence and a high proportion of metastatic cases at diagnosis.
- NETs of different organs have distinct variation in incidence and survival. This stresses the importance of individualized multidisciplinary case management.
- The incidence of NETs is rising in New Zealand. This rise is evident over the relatively short time period of 5 years.
- We believe this is the first analysis of NET incidence conducted on a complete national population, and therefore offers a level of accuracy not previously available.

References

1. Statistics New Zealand Census Data 2013 / 2006
2. Dasart, A. et a. Trends in the Incidence, Prevalence and Survival Outcomes in Patients with Neuroendocrine Tumours in the United States. JAMA Oncology, April 2017
3. New Zealand Ministry of Health Cancer: New registrations and deaths 2013

Kate Parker
kate.parker@auckland.ac.nz