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Monday 6 – Tuesday 7 December 2021

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19th Annual Meeting of the UK and Ireland Neuroendocrine Tumour Society 2021

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CONTENTS

Oral Communications

OC1

Incidence, prevalence of survival of neuroendocrine neoplasia in England 1995–2018

Benjamin Easton White[1,2], Kandiah Chandrakumaran[1], Kwok Wong[3], Brian Rous[4], Catherine Bouvier[5], Mieke Van Hemelrijck[6], Rajaventhan Srirajaskanthan[7] & John K Ramage[1,7]
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Introduction
Incidence of neuroendocrine neoplasia (NEN) is rising worldwide. The National Cancer Registry and Analysis Service allows accurate study of NEN in England.
Aim
Calculate incidence and prevalence of NEN in England from 1995-2018. Calculate site-specific survival with multivariate analysis.
Method
A population-based retrospective cohort study was performed. Data requested from NCRAS were reviewed by a steering group run by Neuroendocrine Cancer UK. Goblet cell carcinoma were excluded. Only 2012–2018 NEN were included in main analysis group due to improved recent coding quality. Eight main primary sites were formed. Merkel and adenoneuroendocrine were excluded. Grade was missing in 31% therefore 'derived morphology' groups were formed termed neuroendocrine tumour(NET) and neuroendocrine carcinoma(NEC).
Results
64,437 NEN were recorded in England between 1995-2018. Age standardized incidence per 100,000 rose steadily from 2.50(95%CI: 2.35–2.65) in 1995 to 8.87(8.61–9.12) in 2018. 5-year prevalence of NEN was 13,439. 19,952 NEN between 2012–2018 met criteria for survival analysis; 51.9% female. Median age 65 years (IQR: 52.0–73.0). Most common sites were lung and small intestine. 76.1% were neuroendocrine tumours(NET) and 23.9% neuroendocrine carcinomas(NEC). Incidence rose in all GEP-NEN sites. Lung NEN plateaued and decreased slightly since 2014. Median follow-up for 19,952 tumours was 2.88 years(IQR: 1.35–4.96). Overall survival was 5.62 years(95%CI: 5.57–5.67). Survival for NEC was 2.62(2.52–2.71) years and NET 6.60(6.55–6.65) years. Site specific survival showed appendix 7.41(7.33–7.48) years, small intestine 5.79(5.69–5.90), rectum 5.782(5.605–5.959), lung 5.188(5.089–5.287), pancreas 5.004(4.871–5.138), stomach 4.697(4.497–4.897), caecum 4.676(4.385–4.966), colon 3.374(3.096–3.652). Black people had survival of 6.59(6.32–6.86) years, Asian people 6.515(6.27–6.75) and White people 5.52(5.47–5.58). The most deprived quintiles had worst survival of all deprivation indices. Sex, ethnicity, deprivation, dwelling(rural/urban), site/stage of tumour and derived morphology were all significant predictors of survival in multivariate analysis.
Conclusion
This analysis of 19,952 NEN in England shows a number of significant factors affecting incidence and survival. More research should be done on these factors.

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OC2

Tracking circulating cell free tumour derived DNA in patients with neuroendocrine neoplasms

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Introduction
There is a clinical need to develop novel and better biomarkers to monitor patients with neuroendocrine neoplasms (NENs). Our aim was to identify and track plasma circulating cell free tumour derived DNA (ctDNA) in a cohort of patients using a personalised, patient specific approach.
Materials and methods
35 serial plasma samples were collected from 9 patients with metastatic NENs (6 small intestinal and 1 each of lung, ovarian, and pelvic; range 2-5 plasma samples per patient) over the space of 2-25 months from a single centre. For each patient, NEN specific somatic mutations (single nucleotide variants and insertions/deletions) were identified through whole exome sequencing of paired tumour-leucocyte DNA and were used to design a bespoke multi-variant Ampliseq™ HD ctDNA panel (5-20 variants per patient) for targeted next generation sequencing. Imaging and treatment were provided as per usual clinical care.
Results
ctDNA was detectable in 6/9 patients and in 19/35 plasma samples. A rise in the number of ctDNA target variants and/or variant allele frequency was seen in 4/6 patients who experienced disease progression. Two of these patients received peptide receptor radionuclide therapy after which ctDNA disappeared in 1 patient and substantially reduced in the other, which correlated with treatment response. The 3 patients who did not have detectable ctDNA at any time point all had grade 1 small intestinal NETs with stable disease during the observation period.
Discussion
Our data provide exciting evidence for the feasibility of utilising ctDNA as a biomarker in NENs. Using a personalised panel assay, we have demonstrated that ctDNA can track changes in disease burden and can monitor response to treatment. Of equal importance, ctDNA was not detectable in patients with quiescent disease. This could be helpful in identifying patients who do not need intensive monitoring. Targeting bespoke, multiple variants per patient is a novel and powerful approach for NENs, as targeting single variants through techniques such as droplet digital PCR may risk missing the dominant tumour variant(s) circulating in plasma. This study provides important early evidence that ctDNA may be a clinically useful biomarker for surveillance in NENs.

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OC3

An update on the effects of debulking surgery and liver directed intra-arterial therapies on quality of life in patients with metastatic neuroendocrine tumours

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Background
Neuroendocrine tumours (NETs) arise from neuroendocrine cells, they are commonly found in the pancreas, small bowel and lung. They are a heterogeneous group of tumours capable of secreting a variety of hormones, therefore the spectrum of symptoms is broad. Treatment options for metastatic NETs include cytoreductive surgery, or interventional radiology procedures such as transarterial embolization (TAE).
Aims
Previous studies have shown that debulking surgery for patients with functional NETs can reduce symptom burden. This study aimed to explore the effect that cytoreductive surgery and liver directed therapies had on quality of life (QOL) over a two-year period for patients with functioning and non-functioning NETs. The secondary aim was to investigate how long it takes for patients to recover QOL post intervention.
Methods
The study was a non-interventional prospective cohort study carried out at a single site; patients received treatment according to routine practice of the clinical team. Participants filled out two QOL assessments (EORTC QLQ-GINET21, EORTC QLQ-C30 V3) and one health status questionnaire (EQ-5D-3L) at pre-op, post-op and then 3 monthly for two years.
Results
22 participants were included in the study, 19 of these completed over 60% of the follow up questionnaires, the median age was 69. 16 patients were treated with debulking surgery, and 6 received liver directed therapy. We have already shown that QOL dips after treatment but returns to above baseline at 3 months. [1] We will present the full 2 year follow up for all patients, exploring long term QOL outcomes after these palliative procedures. This will provide real world data for counselling on these interventions, enabling patients to make informed decisions about treatment, and provide a realistic view of the post-procedure recovery period and the two years that follow.
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1. Sinclair A, Tanno L, Jarvis E, Ramsey E, Naheed S, Armstrong T, Takhar A, Knight J, Stedman B, Modi S, Bryant T, Breen D, Nolan L, Al-Mrayat M, Pearce N, Cave J, The effects of debulking surgery, transarterial embolisation and transarterial chemoembolisation, on quality of life (QOL) in patients with metastatic ileal and pancreatic neuroendocrine tumours, [Poster] UKINETS conference 2nd December 2019, Birmingham UK.

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Poster Presentations

P1

Setting up of a national liver transplant programme for neuroendocrine tumour liver metastases in UK and Ireland: opportunities for clinical study and research

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Background
Transplantation for cancer indications is evolving rapidly in UK and Ireland. Liver transplantation [LT] for unresectable neuroendocrine tumour liver metastases [NET LM] is one of three new cancer indications. It has the potential to significantly improve survival outcomes however, transplant benefit has likely been achieved only by highly experienced Centre(s). Since eligible patients for transplantation also have excellent prognosis with standard management, careful patient selection [Table 1] and meticulous management is required to prevent harm.
Aims
To achieve enhanced overall survival and deliver an equitable and safe service. To develop national infrastructure and expertise for NET LT; promote scientific collaborations and clinical studies/trials; ultimately deliver a randomised clinical trial of transplantation v standard care.
Progress
Framework, infrastructure and manpower
- Documentation completed – patient information sheet, programme manual, patient pathway document, referral proformer, data fields.
- Core National MDT formed and participants from liver transplant / NET Centres identified.
- Infrastructure arranged – MDT room and IT support for combined physical/virtual participation.
- Administrative support arranged – MDT co-ordinator, NET CNS, liver transplant co-ordinator, data manager.

Monthly MDT commenced 27/08/2021; 2 meetings held to date and 4 patients discussed – 2 suitable for commencing liver transplant pathway. 2 deemed not suitable due to unresectable primaries. tems for further development identified – checklist of essential points for discussion, formal patient presentation document containing opinions of relevant specialists.
Conclusion
National programme of LT for NET LM has commenced. There is a need for dissemination of eligibility criteria to all NET specialists in order to make the programme equitable and fair.

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P2

Vitamin deficiencies in patients with neuroendocrine tumours

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Background
Neuroendocrine tumours (NETs) are a heterogenous group of slow growing tumours with an increasing incidence. Disease-related diarrhoea, surgery and medical treatment can lead to malabsorption, resulting in vitamin deficiencies.
Objective
To establish the prevalence of vitamin deficiencies in patients with NETs.
Method
Retrospective review of NET patients seen since 2014 in South Wales across 6 health boards. Deficiencies in vitamin and micronutrients were identified on blood results at any time since NET diagnosis.
Results
260 NET patients (120 females, 140 males; median age 69 years). Grades I, II and III detected in 61.9, 21.5, and 1.5% of patients, respectively. Metastasis present in the lymph nodes in 123(47.3%) and the liver in 94(46.2%) patients. Vitamin and micronutrient deficiencies were present in gastroenteropancreatic NETs, particularly in those with a midgut primary. Deficiencies were noted in Vitamin B12(27%), A(9%), D(28%), E(1%), iron(ferritin 17%), folate(11%), selenium(4%), zinc(10%), and copper(1%). Vitamin B12 was present in 45(32.4%) of those with a small bowel resection. 76(49.4%) patients on somatostatin analogue therapy experienced steatorrhea of which 41(53.9%) developed fat-soluble vitamin deficiencies.
Conclusion
Vitamin and micronutrient deficiencies are present in gastroenteropancreatic NETs and may be a consequence of various factors including previous NET surgery, or treatment with somatostatin analogues (causing pancreatic enzyme insufficiency) or the NET itself. Vitamin D deficiency may relate to the background deficiency in the population. Some of these may require monitoring as part of NET care.
Key words: neuroendocrine tumour, vitamin, micronutrient, deficiency
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P3

Sex differences and survival of neuroendocrine neoplasia in England 2012–2018

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Introduction
Sex differences have been noted at different sites of Neuroendocrine Neoplasia in previous registry studies across different countries. Analysis of National Cancer Registry and Analysis Service (NCRAS) data can help to clarify the significance and importance of this factor in England.
Aim
To examine neuroendocrine neoplasia incidence and survival by sex, site and stage.
Method
A population-based, cohort study was performed. Data were requested from NCRAS for 1995-2018 and analysed. Goblet cell carcinoma were excluded from all analyses. NEN diagnoses registered between 2012–2018 were included in main descriptive and survival analyses due to accuracy of recording. Eight main sites were included. Merkel cell and adenoneuroendocrine were excluded from survival analyses. Grade was missing in 31% therefore 'derived morphology' groups were formed termed neuroendocrine tumour(NET) and neuroendocrine carcinoma(NEC).
Results
19,952 NEN between 2012-2018 met criteria for analysis. Of 19,952 tumours, 51.9% were female. Females had slightly more NET (54.1%) and Males more NEC (54.9%). There is a striking preponderance of females in Appendix and Lung NEN. Across main NEN sites the predominant sex were, appendix; female 61.5%, caecum; female 55.6%, colon; male 57.8%, lung; female 60.3%, pancreas; male 54.5%, rectum; male 55.2%, small intestine; male 56.3%, stomach; male 52.1%.

Table 1 Eligibility criteria for liver transplantation.

Pilot phase	1 [0-10 liver transplants]	2 [11-50 liver transplants]
Histology	G1/G2 WD NET	G1/G2 WD NET
Primary site	GEP	GEP + Other
Primary and associated lymphadenopathy	Completely resected before liver transplant surgery	Can be left in-situ if small volume and stable
Liver metastatic burden	<50% by volume	< or > 50% by volume
Disease stability	Stable disease/response to therapies for at least 6 months prior to transplant consideration	Stable disease/response to therapies for at least 6 months prior to transplant consideration
Patient age	< 60 (relative criteria)	< 60 (relative criteria)

Overall survival was 5.17(95% C.I; 5.10–5.24) years for males and 6.01(5.945–6.08) for females. Being female conferred a significant survival advantage in Cox-Regression Multivariate Analysis. Worse survival in males was seen in multiple sites, such as pancreatic NEN ($P = 0.001$). There were significant survival differences by sex in appendix, lung, pancreas, rectum and stomach ($P = 0.001$).
Conclusion
There are large sex differences in incidence at certain sites of NEN in England. These appear to have a significant association with survival. This sex difference is not reflected in data from other types of cancers at the same site, for example adenocarcinoma of the pancreas, where males and females have similar survival. Being male confers significantly worse survival in NEN, particularly in NEN of the pancreas, rectum and stomach. Work is needed to explore the reasons behind this.

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P4

The Impact of the Covid-19 Pandemic on Neuroendocrine (NET) services and patients: A quantitative and qualitative analysis

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Introduction
The response to SARS-CoV-2 lead to interventions to mitigate the pandemic. We retrospectively analysed the effect of changes on key NET services. These included: change in clinic media, absolute change in numbers for endoscopy and bronchoscopy, nuclear imaging, SSA administration and PRRT numbers compared with 2019.
Method
The NET database was analysed. Endoscopy rates on a monthly basis were reviewed. Two bespoke postal patient surveys were created. Survey 1, sent to 70 randomly selected NET patients in June 2020, detailing 38 MCQs pertaining to scheduling, physicians, consultation media, Covid-19 infection, anxiety, preferences and a free text section. Survey 2 related to treatment, satisfaction and preferences of those vulnerable patients who had a switch from hospital to domiciliary SSA.
Results
A total of 695 patients had recorded attendance at NET centre. 630 were follow-up. 20% of these were face to face, 79% telephone, 1.3% video. 42% of new patients attended face to face, 57% were telephone and 1.5% on video. There was a 67 % response rate from survey 1. 2% had tested positive for Covid-19, 60 % liked telemedicine, 93% felt extremely and very well cared for by their NET physicians and were satisfied with their consultations and illness information. 36% reported an increase in anxiety due to the pandemic and 79% felt supported psychologically. Survey 2 reviewed 25 urgent switches to domiciliary analogue therapy. 68% of patients responded. 75% preferred home treatment, 62% would consider continuing with this after the pandemic. Review of the database revealed a fall in PRRT and chemotherapy numbers by 25% and 33% compared with 2019. Bronchoscopy procedures fell to single numbers in April and by 33% overall. Upper GI and LGI endoscopies fell to zero in April and by 55% overall. FDG PET-CT scanning total yearly figures rose by 2%.
Conclusion
There was a reduction in key services. It will be important to ensure rebound of services has occurred and to assess the long term impact of morbidity and mortality of the pandemic in NET patients.

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P5

Real world overall survival in patients with gastroenteropancreatic (GEP) neuroendocrine neoplasms (NENs) in a large United Kingdom (UK) tertiary centre

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Introduction
The incidence and prevalence of GEP-NENs is rising worldwide. NENs represent the group off well differentiated neuroendocrine tumours (NET) and poorly differentiated neuroendocrine carcinoma (NEC). NETs can be divided into grade 1 (G1), grade 2 (G2) and grade 3 (G3) based on histological parameters. There exist several studies regarding survival data but these are mainly based on national databases.
Aim
To describe the real world overall survival of a large UK cohort of patients with GEP-NENs regardless any stage or treatment.
Methods
A retrospective study on all patients recorded in our local database (2000-September 2021) with any type of GEP NEN was performed. Additional data regarding, age, sex, grading and overall survival (OSS) were collected. For OSS the NHS spine was checked on 6 September 2021. Kaplan Meier curves for survival analysis were performed and a log rank test for statistical analysis.
Results
A total of 1158 patients, 589 male (51%) with median age 61 year (IQR 49 – 70 year) could be included. The primary tumour was in the stomach $n = 34$ (3.4%), duodenum $n = 51$ (4.4%), pancreas 388 (33.5%), small bowel 362 (33.1%), appendix $n = 90$ (7.8%), colon $n = 23$ (2%), rectum $n = 55$ (4.7%), gallbladder $n = 3$ (0.3%), oesophagus $n = 2$ (0.2%), ampulla $n = 7$ (0.6%), bile duct $n = 4$ (0.3%) and unknown primary $n = 134$ (11.6%). The tumours were G1 $n = 424$ (36.6%), G2 $n = 217$ (18.7%), G3 $n = 50$ (4.3%), NECs $n = 59$ (5.1%). The median OSS for the entire cohort was 102.6 months and for G1-G3 NETs 126 months. The 5-year survival rate is 60%. There is a significant ($P = 0.031$) difference in OSS for female vs male patients.
Conclusion
This study reports on the median OSS from a real world cohort of patients with GEP-NENs in the UK including also more rare cases such as bile duct, gallbladder and ampulla NENs. Further prospective research is necessary to explore the differences between OSS in this real world cohort and national database based studies.

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P6

Earlier diagnosis of neuroendocrine tumours (NETs) through transformation of the south wales NET service

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Background
Neuroendocrine tumours (NETs) are heterogeneous cancers with varied survival, arising mainly from the gastroenteropancreatic tract. Delayed diagnosis and mislabelling are widely recognised internationally in midgut NETs with little data describing how to improve diagnosis times. In 2017, transformation of the South Wales NET Service included a change to a gastroenterology-led service model alongside education and forming working relationships with gastroenterologists and surgeons in Wales.
Objective
To evaluate times and routes of diagnosis of GEP-NETs in South Wales.
Methods
This was a retrospective study of accurate hospital records for 224 patients with midgut NETs (and unknown primary, likely to be midgut). There were 110 patients pre-transformation and 114 post-transformation.
Results
Median diagnosis time from symptom onset was 13 months pre-transformation, 5.6 months post-transformation ($P < 0.001$). Diagnostic delay over 3 years was 13% pre-transformation, 6% post-transformation. Metastatic disease at diagnosis or soon after reduced from 70% to 55%. 40% of patients were mislabelled as IBS, or other pre-transformation; reducing to 25% post-transformation. 25% were discharged from secondary care prior to re-referral and diagnosis; reducing to 19% after 2017. 82% of patients were diagnosed by gastroenterology or GI surgical specialities. 46% of those presenting as an emergency had chronic symptoms; 47% of these were already being investigated prior to the emergency admission. Symptoms included abdominal pain, diarrhoea, vomiting, flushing and weight loss. 13% of patients were asymptomatic and diagnosed as an incidental finding. Often this was during investigations for other cancers. Only 20% of patients who had colonoscopy as a first line investigation had an abnormality found whereas 96% of cases were diagnosed on abnormalities found on CT.
Conclusion
Diagnosis times of midgut NETs have improved across South Wales. This is likely to be a result of the change in service model, education of gastroenterologists and surgical teams in Wales, increased awareness and efficient use of investigations. Diagnosis rates improve with imaging rather than colonoscopy as first line investigation.

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P7

Sex specific differences in overall survival in patients with pulmonary neuroendocrine neoplasms (NENs) in a large United Kingdom (UK) tertiary centre

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Introduction
Pulmonary NENs account for around 2% of all pulmonary malignancy. They are classified histologically into 4 types typical and atypical carcinoids which are generally well differentiated and large cell neuroendocrine carcinoma (LCNEC) and small cell lung carcinoma (SCLC) which are poorly differentiated. Within the literature there are several reports regarding overall survival on small mainly surgical cohorts, but data for the UK population are lacking. Only a few studies looked into differences between male and female patients and reported no differences in survival.
Aim
To describe the survival of a large UK cohort of patients with pulmonary NENs regardless any stage or treatment.
Methods
A retrospective study on all patients recorded in our local database (2000-September 2021) with any type of pulmonary NEN was performed. Additional data regarding, age, sex, grading and overall survival (OSS) were collected. For OSS the NHS spine was checked 6 September 2021. Kaplan Meier curves for survival analysis were performed and a log rank test for statistical analysis.
Results
Since 2000 there has been an increase in number of patients from a few yearly to 22 in 2019. A total of 147 patients, 59 males with median age 64.1 (interquartile range 53 – 74 year) could be identified. These were classified as 73 typical- , 43 atypical carcinoids, 8 DIPNECHs and 4 LCNECs, 3 SCLCs and 1 poorly differentiated carcinoid. At cut-off of the study 90 patients were still alive. The median OSS for the entire group is 119 months (IQR 57.3 – 180.7), the 5-year overall survival rate is 76%. There is a significant difference in OSS for patients with typical versus atypical carcinoids ($P < 0.001$) as well between male and female patients (P 0.026).
Conclusion
This study reports on the overall survival in patients with pulmonary NENs regardless staging or treatment in the UK. All newly diagnosed patients with a pulmonary NEN could benefit from expert centre input. The OSS survival differences between male and female patients has not been described before, but is in line with findings from the national NCRAS database, factors leading to this difference in survival needs to be better understood.

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P8

A 10 year retrospective review of pulmonary neuroendocrine tumours (PulNETs/Carcinoids) in a european tumour centre of excellence

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Introduction
Pulmonary neuroendocrine tumours (pulNETs) histologically encompass: small cell, large cell, typical (TC) and atypical carcinoid (AC). Diffuse idiopathic pulmonary neuroendocrine hyperplasia (DIPNECH) is a very rare condition but potentially progress to pulNET and is associated with MEN. Advances in treatment have modified management, and there have been recommendations to use Ki67 for grading. However there is a paucity of randomized studies.
Method
A retrospective analysis in the form of a search using the key words/codes 'atypical and typical carcinoid' was performed on the Apex histopathology database for cases between Jan 2009 to Dec 2019. All cases found on the Apex histopathology database were collated. Electronic records, histopathology and biochemistry were reviewed.
Results
97 cases were found. Of those: 17AC (17%) and 75TC (77%). DIPNECH was found in a further 3 patients. 85 patients had Ki67 analysed to grade the NET. Grading was carried out according to WHO 2015 classification as G1(49), G2(32), G3(7),no data in (9). In terms of imaging and staging, 97patients (100%) had undergone CT TAP, 86 had FDG PET and 11 had SSTR scintigraphy (Gallium 68 PET or Octreoscan). In terms of staging at presentation 64 were PT1, 22 were PT2, (6) PT3 and 5 was PT4. Surgical procedures included: 35 VATS, 48 thoracotomies. As for follow up, 81 had CXR,7 had CT surveillance under respiratory physicians. In terms of biochemistry chromogranin A was performed in 5 patients. 4 received somatostatin analogue therapy, 4 had chemotherapy, 4 had radiotherapy and none had targeted treatment. 2 % were MEN 1 gene positive. The number of deaths were 27 and those under active follow up were 31 and 39 were discharged. 12 patients were listed at the NET MDT after 2016.
Conclusion
According to our analysis, histopathological review carried out in patient was according to the WHO classification, met criteria for gold standard, immunohistochemistry and WHO grading 2015 was done as well. 100% of patients received imaging with CT scan. NET MDT was only performed in limited number of patients as this was set up since STH becoming Centre of excellence in 2016.

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P9

Frontiers in Carcinoid Heart Disease

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The treatment of patients with carcinoid heart disease (CHD) presents substantial challenges due to the advanced multisystem nature of their disease. Intensive multidisciplinary collaboration and innovative techniques are often required in order to manage these patients. Here we describe two such cases from our institution. A 59-year old gentleman with metastatic NET and CHD was referred to our centre. Transoesophageal echocardiography demonstrated severe tricuspid regurgitation and a patent foramen ovale (PFO) with left to right flow. During induction of anaesthesia for valve replacement surgery he became severely hypotensive and hypoxemic, consistent with a carcinoid crisis. Surgery was abandoned and he was transferred to the intensive care unit where he remained persistently hypoxemic. Bubble echocardiography demonstrated shunt reversal with right to left flow across the PFO. He underwent percutaneous PFO closure under local anaesthesia guided by intra-cardiac echocardiography (ICE) which led to rapid resolution of hypoxaemia. He recovered well and underwent successful tricuspid and pulmonary valve replacement surgery 3 months later. The second patient was a 69 year old male with CHD who underwent tricuspid and pulmonary valve replacements. Twelve hours post operatively he developed episodes of unprovoked hypotension and bronchospasm consistent with carcinoid crisis. After initially responding to octreotide he went into cardiac arrest. Following emergency resternotomy in the ICU he was placed on peripheral VA ECMO. Treatment for his carcinoid crises was maximised and on day 10, whilst on ECMO he underwent selective hepatic artery embolization of his liver metastasis in an attempt to further reduce his tumour burden. On day 17 post op he developed worsening biventricular dysfunction during an attempted ECMO wean. Following MDT discussion, and with his family's agreement, treatment was withdrawn and he died on post op day 18. These cases illustrate some of the novel techniques that can be used to aid the management of patients in extremis with carcinoid heart disease. Due to the relatively low numbers of cases, a further collaboration is required amongst centres of excellence and it calls for an international registry to be developed to improve care in this patient group.

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P10

Addressing professional development needs in neuroendocrine cancer nursing

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Adult Neuroendocrine Cancer nursing is a highly specialised field where expertise in both knowledge and appropriate skills can make a significant contribution - 'especially in the promotion and maintenance of high standards of practice, education for the patient' and the application of safe evidence-based knowledge and skills 'the patient requires when diagnosed with a rare disease' (1). Whilst considered rare, Neuroendocrine Cancer has seen an exponential growth in incidence, in the UK - from approximately 2:100,000 in 2001 to 9.37:100,000 in 2017 (2). Studies have found that the presence of a specialist nurse has the potential to support a more positive patient experience (3). Yet, research suggests that many nurses, even those within the field, lack confidence in supporting those diagnosed with Neuroendocrine Cancer (4). There is also an identified gap in nurse education regarding Neuroendocrine Cancers - the topic is not included in past or current oncology nurse curriculum, nor covered within other formal nursing education courses. Following on from the RCN accreditation of the

Neuroendocrine Cancer Nurse Competency Framework, an online educational resource was proposed. A literature review and examination of available courses was undertaken. This led to the establishment of a faculty of specialist nurses, patient experts and AHPs to develop a programme of learning: an overview of Neuroendocrine Cancers with 4 site/system specific modules (to start) : Lung, Upper GI, Lower GI and Skin. The NCUK Academy aims to guide participants, from basic awareness to encouraging a deeper understanding of Neuroendocrine Cancers: enhancing knowledge, problem-solving and critical thinking skills. In Autumn 2021, the Academy - a competency-based, CPD accredited, modular programme - was launched. Formal evaluation of the programme is ongoing and further modules will be added over time.

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P11

Survey of neuroendocrine tumour patients' experience of quality of care provided by a dedicated NET dietitian

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Background
The Birmingham Neuroendocrine Tumour (NET) service has a full time dedicated NET Dietitian for outpatient and inpatient care since August 2020. An anonymised survey of patient experience was performed to identify ways in which we can improve the service for patients. 87 potential patients were identified. 8 had passed away. 79 questionnaires were sent out. 38 were returned via a self-addressed envelope.
Results

- 53% of patients were first referred to the NET Dietitian by NET CNS', 34% by a NET consultant, 8% were walk-ins in clinic, 2.6% requested a Dietitian review whilst the remaining 2.6% first met the NET Dietitian in hospital.
- 97% of patients found the time between referral and first consultation was acceptable. 39% of patients were seen face to face, whilst 61% were spoken to over the telephone. This was prominently due to the Covid 19 pandemic. 89% found the way in which the first consultation was carried out was suitable.
- When asked if the NET Dietitian was knowledgeable about their condition, 26% completely agreed, 53% of agreed whilst 21% were 'in-between' agreeing and disagreeing.
- When asked if the NET Dietitian put them at ease and made them feel comfortable to talk freely as well as listened to their concerns and needs, 51.5% completely agreed, 43.5% agreed, 3.8% were in between and 2.6% disagreed.
- When asked if the NET dietitian's advice was tailored to them and their lifestyle, 39% completely agreed, 45% agreed whilst 13% were in between.
- 97% of patients felt they had sufficient time to speak to the NET Dietitian and 53% of patients felt the care they received from the NET Dietitian improved their overall health.
- 29% felt the frequency of stools improved a lot, 45% said the consistency of their stools improved a lot, 37% reported an improvement in the colour of their stools by a lot. Other areas which patients reported an improvement included wind/ bloating, abdominal pain, weight gain, range of foods eaten, vitamin and mineral levels, quality of life and finally mental health.
- Only 2.6% of the respondents were from non-native, reflecting our population.

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P12

Do patients with small bowel NET tend to be diagnosed late and with advanced disease?

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Patients with small bowel NET may present in a different way from other GPNET patients, with well-established disease and metastases. They may have long term symptoms that are well investigated but remain undiagnosed sometimes for years. To examine this supposition the presenting symptoms and outcomes of the first thirty patients with small bowel NET seen in 2018 were examined. Of these thirty patients eight were female and twenty-two were male with a median age of 64.5 years (range 48.5 to 75.6 years). Fourteen patients had their disease discovered incidentally (two at bowel resection). Six had a bowel resection (two now with nodal recurrence, four no recurrence) and eight no resection. Of the eight who did not have a bowel resection one died soon after, the remainder having stable disease on SSA injections. Seven patients presented acutely with abdominal pain (3), bleeding (1), bowel perforation (2), or obstruction (1). This led to four Right Hemicolectomies, two small bowel resections and one ileostomy (who died). Two patients have no recurrent disease on surveillance. The four remaining all have metastatic disease. Three patients are stable on SSA. The third category is six patients who had long term symptoms, of anaemia (1), weight loss (2) or abdominal pain (3). This type of patient is that thought may be undiagnosed for a long period of time, presenting with advanced disease. The patient with anaemia had a number of investigations before diagnosis. One patient had precipitous weight loss over weeks, the other over two years. Three patients presented with abdominal pain (two also with weight loss) and had a small bowel resection. The pain symptom was present for either years (2) or a few weeks (1). One died from slowly progressing disease, the others show no sign of disease recurrence. In the final category of three patients the original histological diagnosis was made between two and seven years ago. There is little information available concerning presentation and symptoms so little inference can be drawn. It would appear that patients presenting with well-established disease and metastases and long term symptoms may not be as common as historically.

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