

Turning it around: The South Wales Neuroendocrine Cancer Service, developing a patient-centred service through co-production



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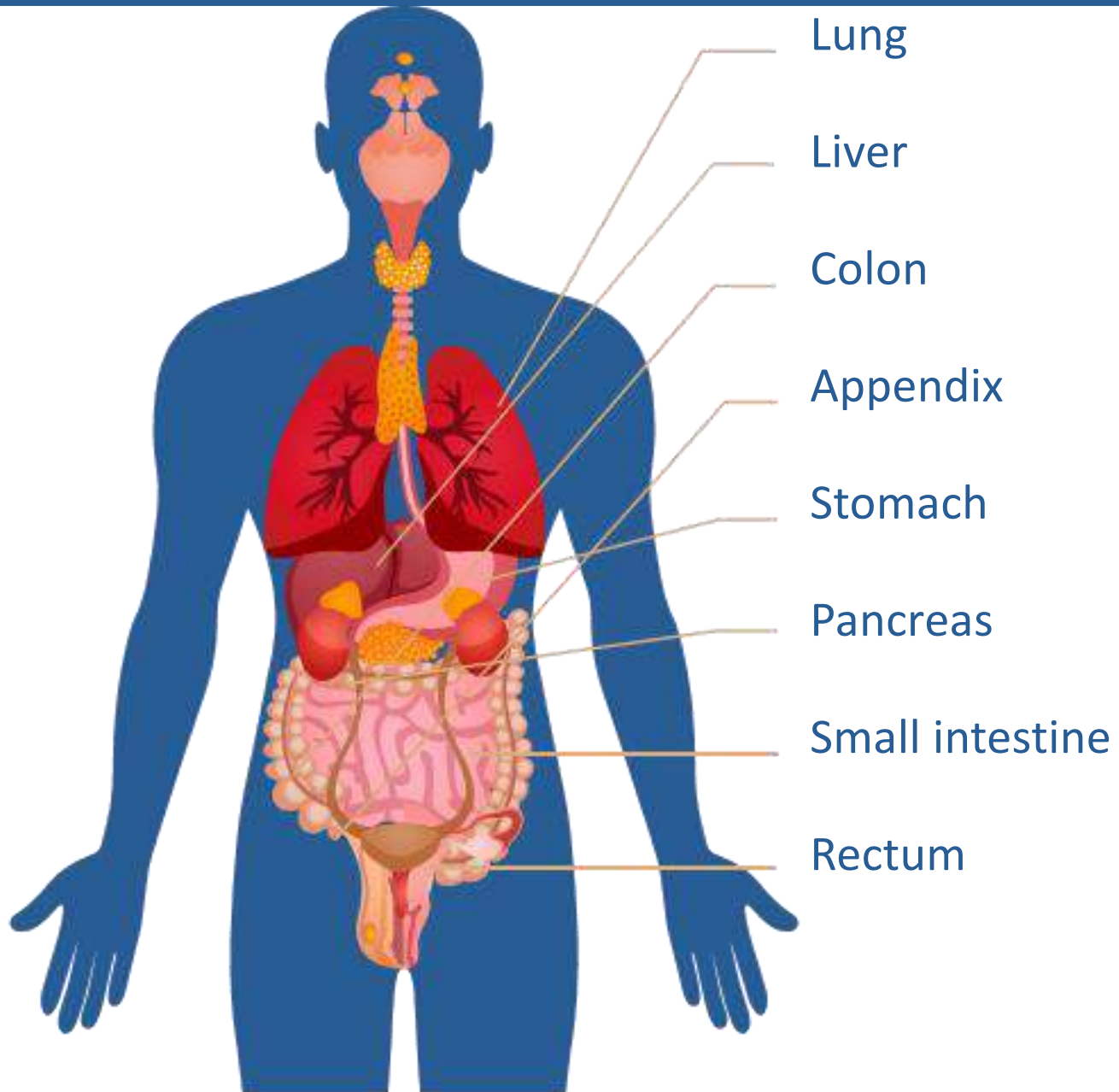
Neuroendocrine Tumour (NET)

Or

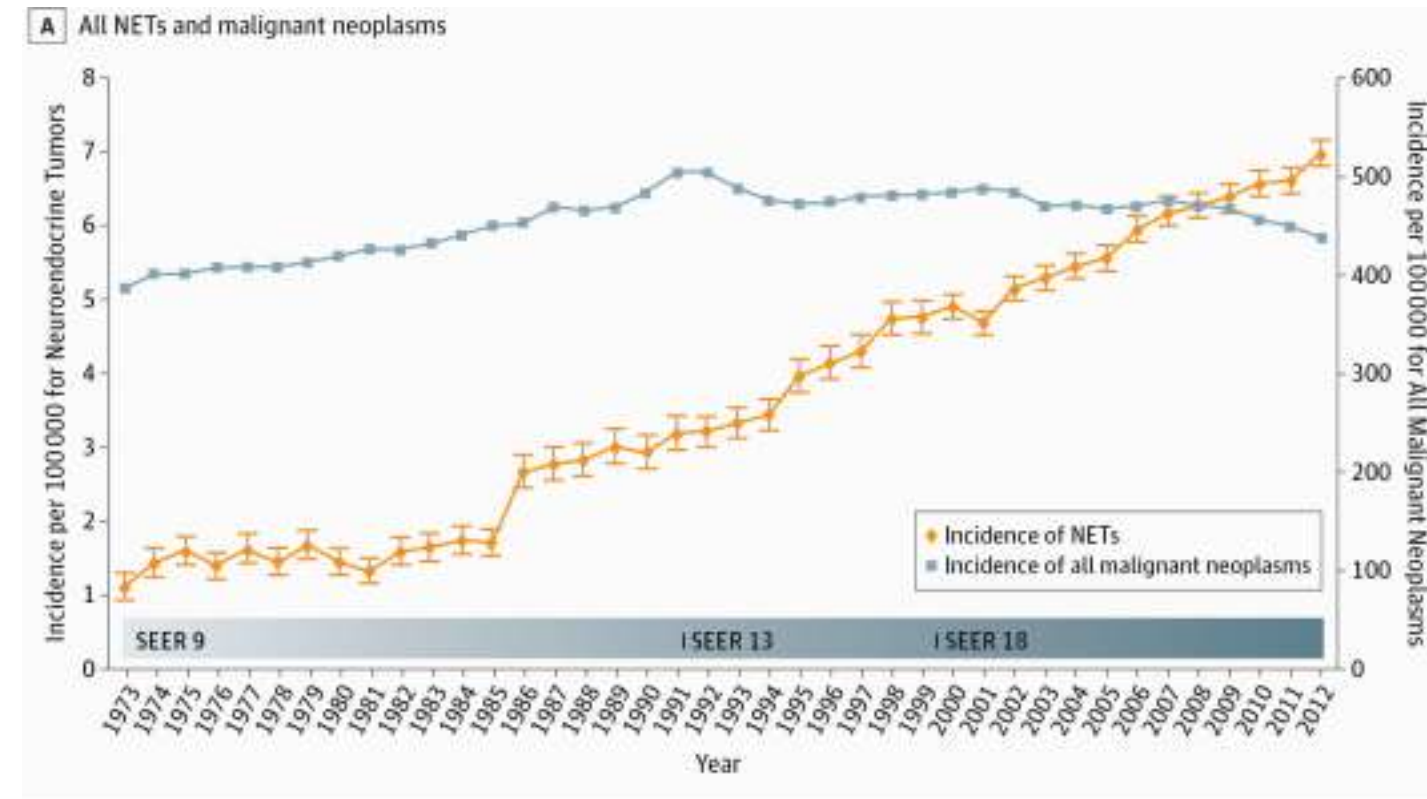
Neuroendocrine Neoplasm (NEN)



NETs: Sites of Tumours



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Incidence of NETs is increasing

Powys Teaching

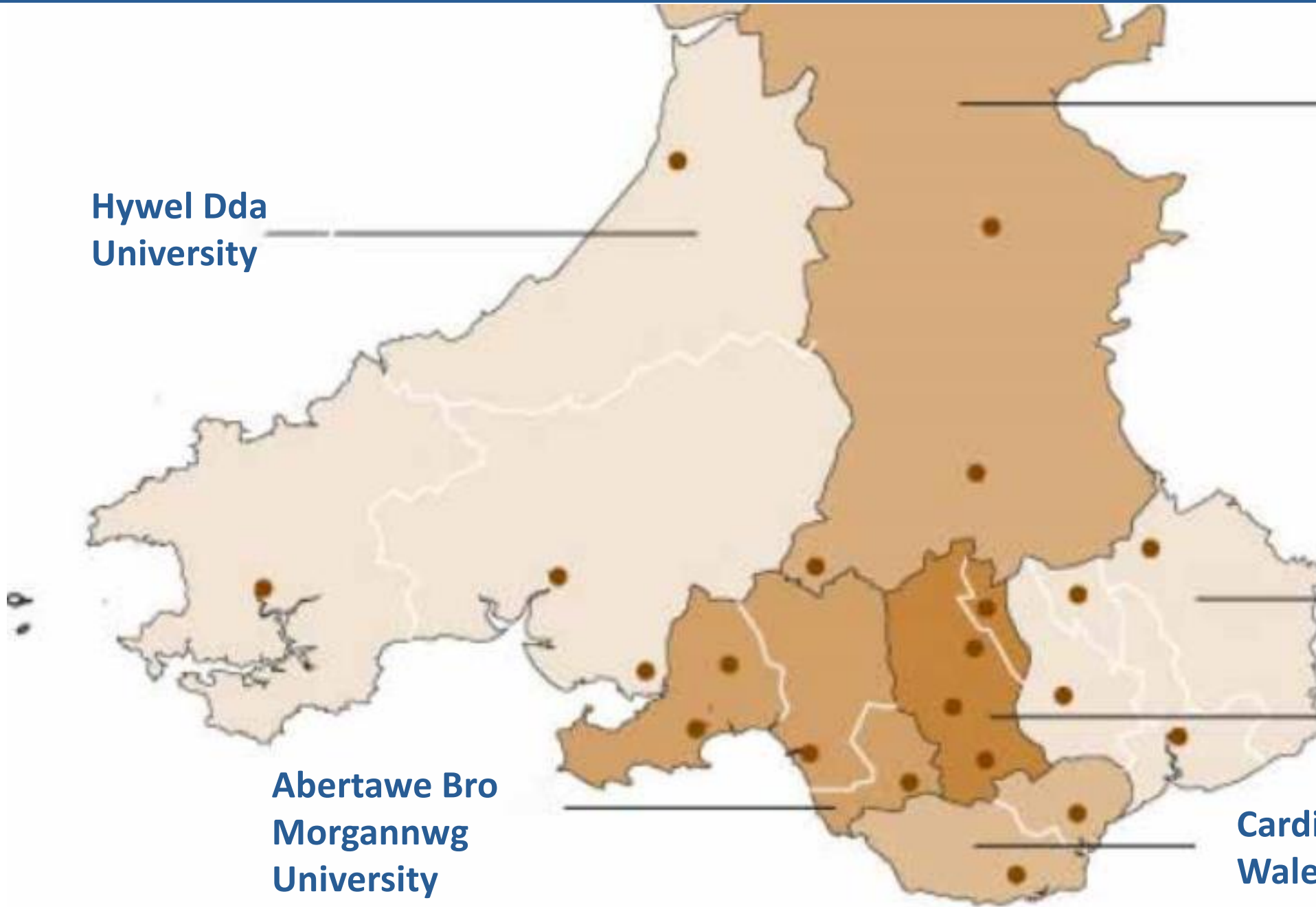
**Hywel Dda
University**

**Aneurin Bevan
University**

**Cwm Taf
University**

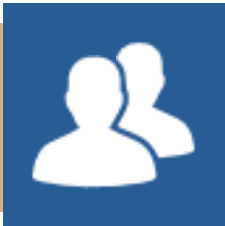
**Abertawe Bro
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**Cardiff &
Wale University**



Historic service – listening to patients

An historic, fragmented service existed with inequalities across health care organisational boundaries in South Wales



NET Patient Foundation Survey



Little nurse input, sparse information



Poor access to specialist investigations and treatments



Lack of confidence in specialist expertise



Lack of attention to (gastrointestinal) symptoms and quality of life



Poor communication and coordination from the NET MDT meeting

This resulted in an overall satisfaction score of 19% and a high burden of gastrointestinal symptoms which were unaddressed

WHSSC: Task and Finish Group

'Task and Finish Group' set up by WHSSC to explore the patient survey with representatives from patient groups, the wider UK NET patient foundation (NPF) charity and clinicians from various specialities across Wales including experts



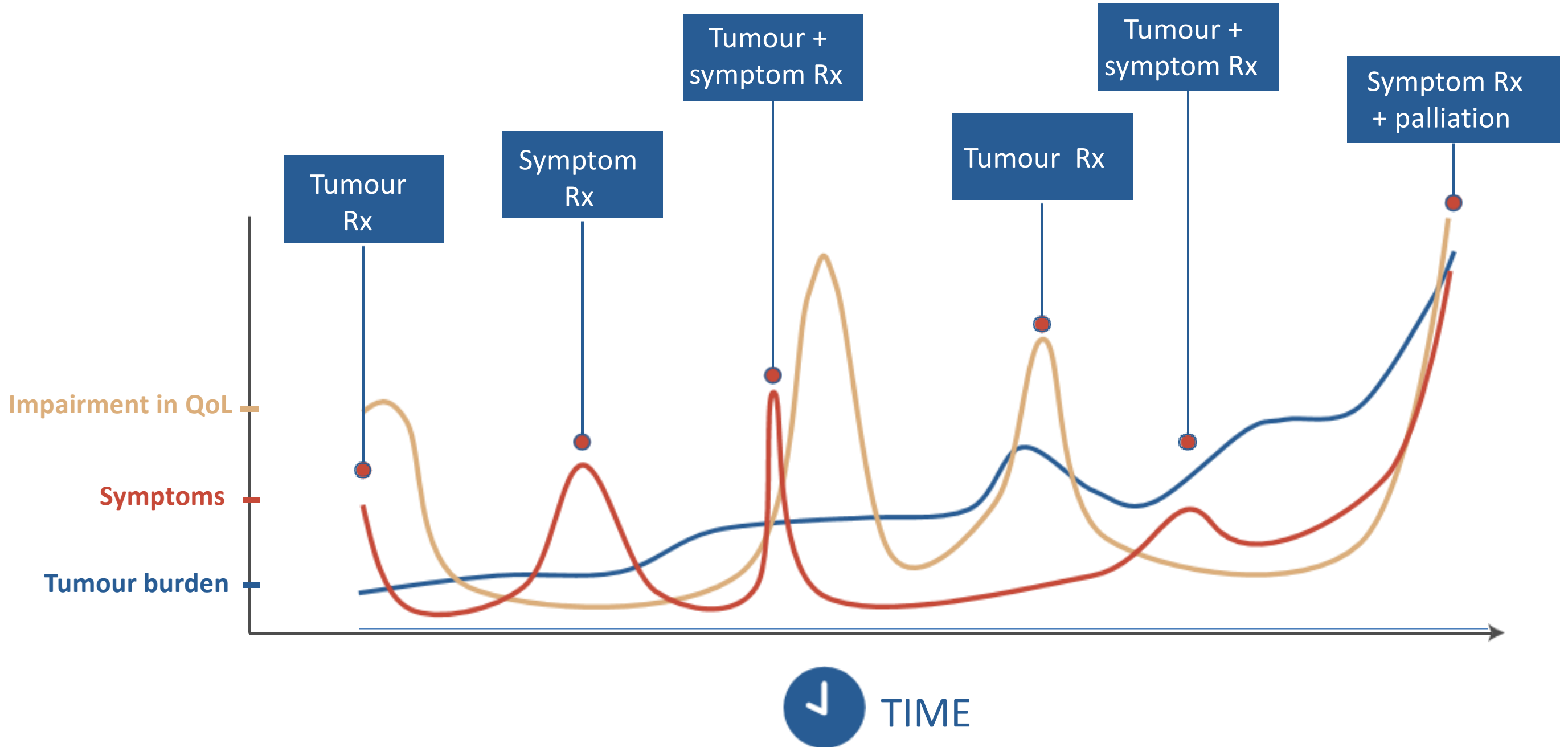
Options for a service model were appraised by the wider group of patients and their carers in Wales, in addition to commissioners and experts from international (European NET Society) centres of excellence.

As the service was implemented, regular stakeholder partnership meetings were held informing patient groups of updates, and asking for ongoing feedback into the service on an iterative basis.



Led by an expert from an international centre of excellence, a gastroenterology-led service was nationally commissioned across 7 NHS boards or trusts (incorporating 16 hospitals) in S Wales centrally from Cardiff.

Natural History



MDT (Multidisciplinary Team) Meetings



Vetting of referrals to appropriate places and clinical responsibility



Immediate initial feedback to referrer



Addition of GI radiology, increased Gallium PET, more regular PB/HPB surgery with fractions of sessions available



Minutes back to referrer and on portal/WCP



Proforma updated, information storage



CANISC capture, coding



Avoidance of repeated discussions by preparation

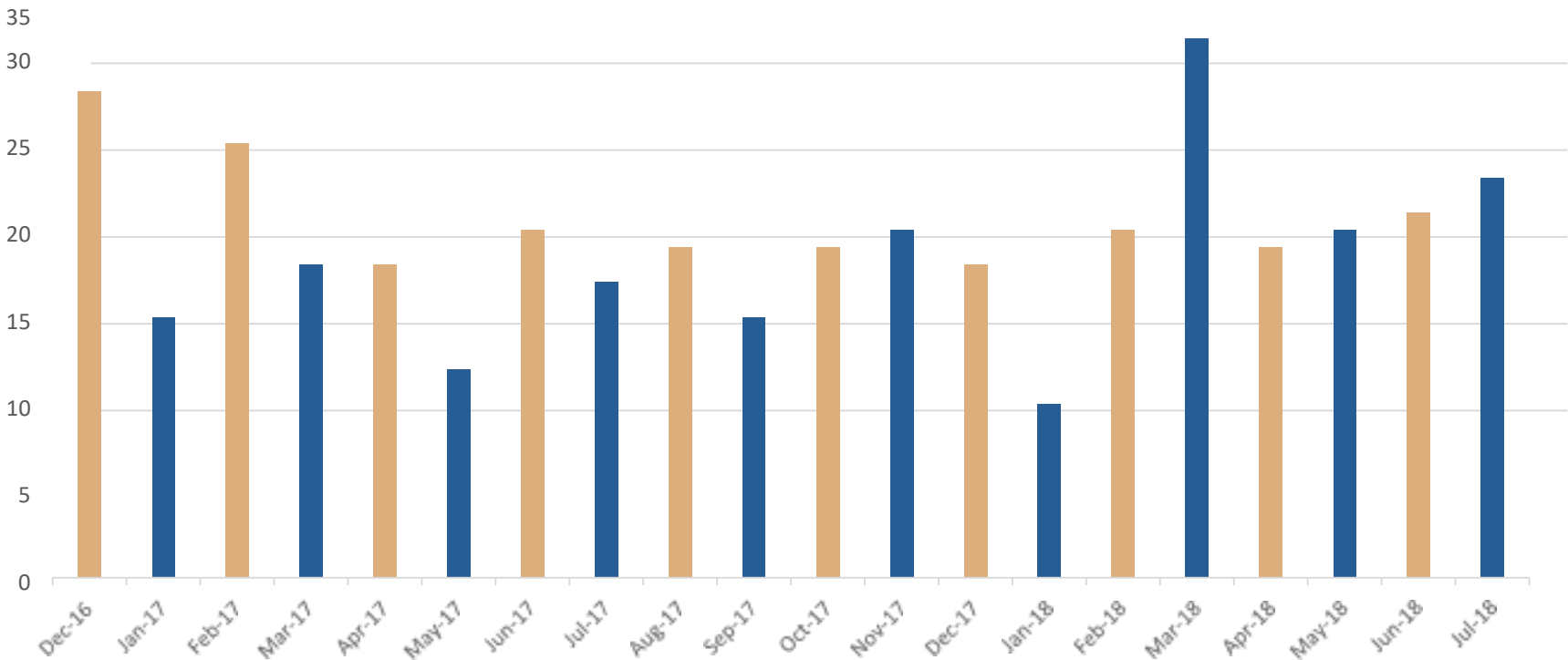


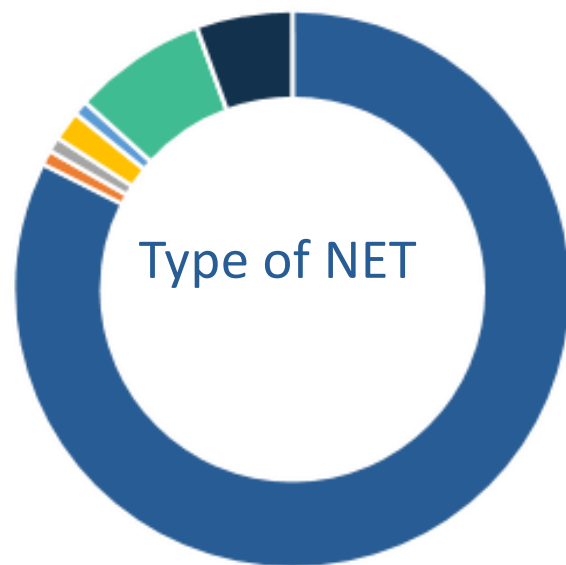
Positive feedback from HB referring clinicians on MDT processes and engagement on how they would like outcomes



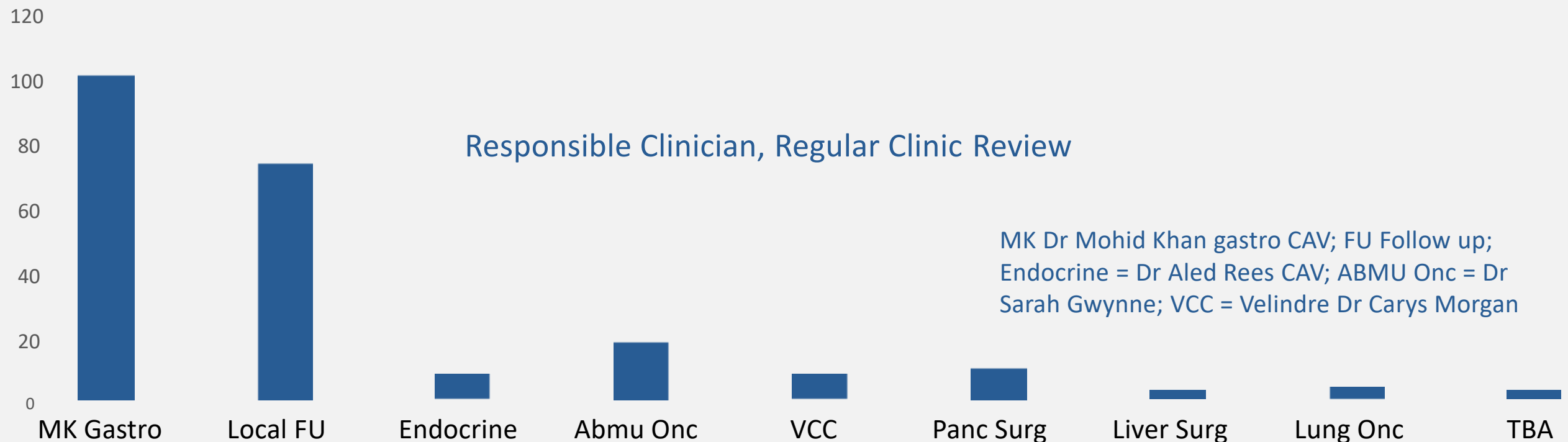
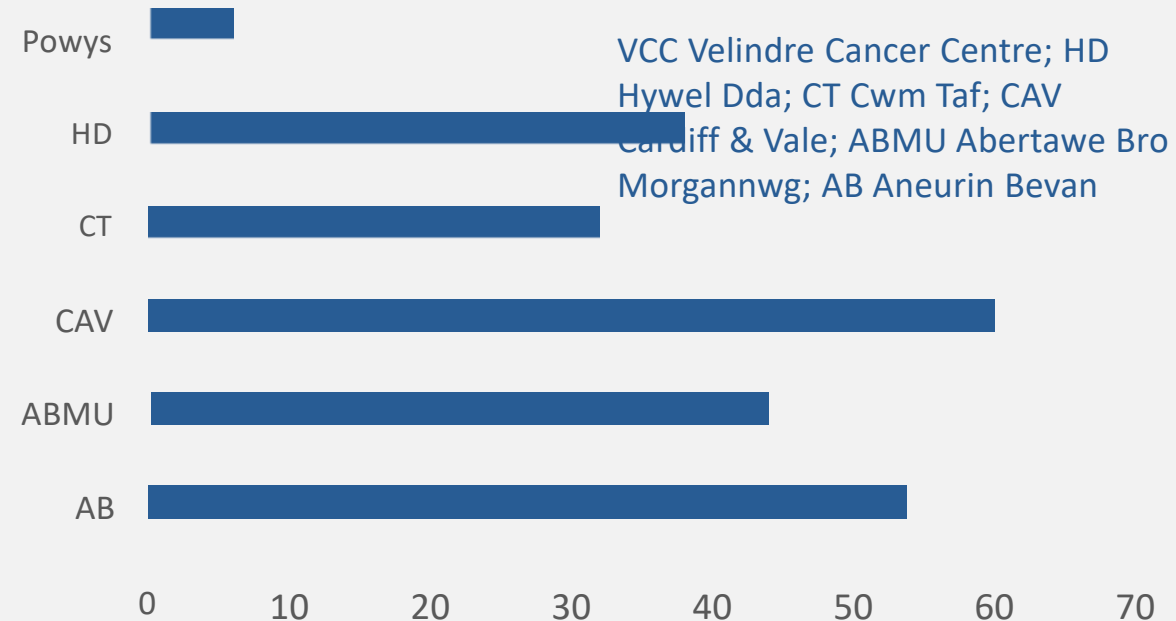
Increased frequency to twice monthly

NET MDT numbers discussed





- Paraganglioma
- H&N
- Gynae
- Bronchial
- Suspected NET
- GEPNET



NET Specialist Clinic – Access to Expertise



Dedicated NET clinic at Llandough

Twitter survey: 74% patients will travel >100miles for NET expertise



Seeing 42% of whole new cohort + pre-existing patients



Seeing all appropriate patients apart from West ABMU



Pre-clinic meeting



Treatment plans of new and FU patients



Use of other HB IT portals, WCP for Wales-wide clinical data



GI and holistic symptoms considered



PROMS



CIT



CNS support



Surveillance, somatostatin analogues, PRRT referrals

South West Wales

- 8% of new cohort to ABMU Oncology
- **ABMU Virtual Clinic with oncology:**
 - >100 cases reviewed, further 200-300
 - PROMS, symptom questionnaires to 'triage'
 - Outcomes
- Improved communication with ABMU oncology, surgery, palliative care and HD
- Responsibility for Bridgend patients in CAV

South East Wales Oncology

- New GI Oncologist (previous complaints)
- 3.5% of new cohort seen by VCC
 - Defined as requiring chemo/radio/sunitinib
 - Existing patients passed on CAV NET clinic if appropriate
- Other site oncology for poorly differentiate NECs

Endocrinology (Cardiff)

- Endocrinology seeing 'endocrine-type' NETs in own clinic
- 3.5% of new cohort seen
- Existing GEP-NET patients in endocrine clinic
- 57 passed to Gastro NET clinic, 31 died leaving 20 patients
- 18 pre-existing MEN1 with NETs

Training and education

- Training of surgeons, gastroenterologists, link nurses and palliative care, primary care

Patient Information & Support

- NPF information, website
- South Wales information leaflets (digital marketing)
- Signposting database across South Wales
- Clinic boards (UHW, UHL, ABMU)
- Other charities e.g. Macmillan, Tenovus, benefits
- Stakeholders meetings



CNS (Cancer Nurse Specialists)



Training – formal, courses, London, Liverpool, conferences, informal teaching



Clinic experience



Nurse led clinic (with supervision)



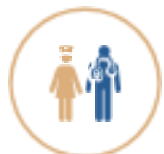
Somatostatin analogue (SSA) injection SOPs



Helpline and generic email supporting regardless of postcode



Endocrine nurse handover



Keyworker and links with 'link nurses' in each HB



Follow up/surveillance protocols for simple cases

Repeated Patient Feedback Survey

Patient Satisfaction



Overall patient satisfaction rate improved from 18% in the old service to 99%

Access to Treatments

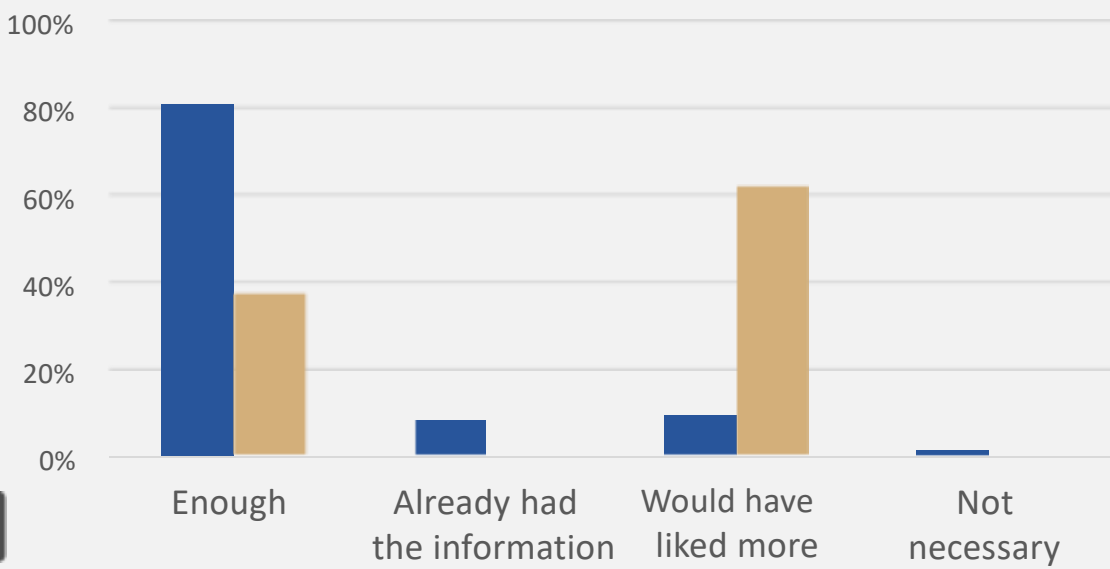


Patients reporting difficulty in accessing treatment reduced from 40% to 12%

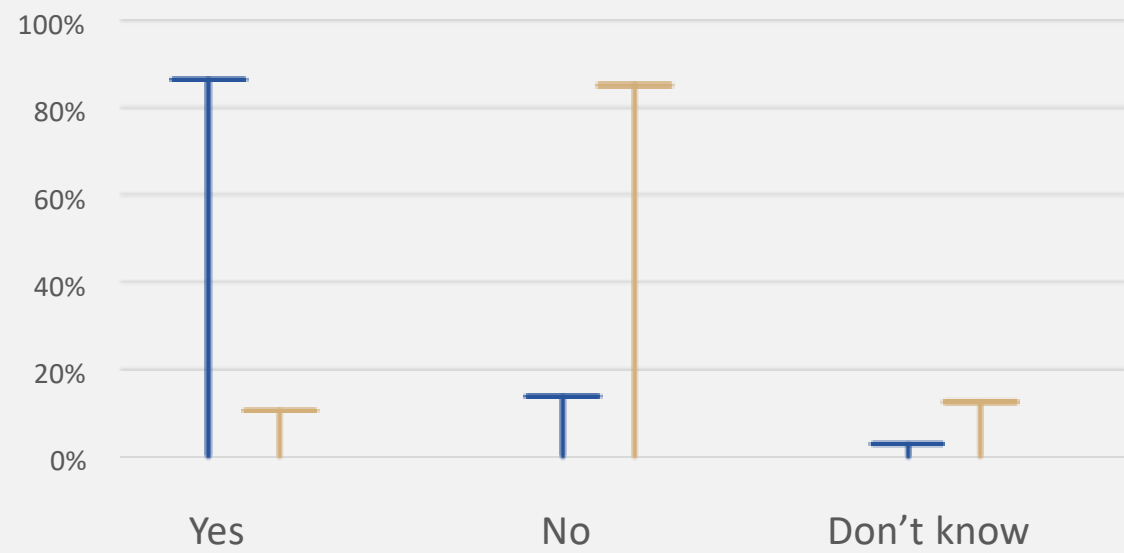
Old Service

New Service

How much information were you given about your condition?



Do you have access to a NET Clinical Nurse Specialist



a

b

Qualitative analysis of feedback

Word clouds created using free text response in survey.



(a)

For the old service and



(b)

For the new service.

Gastrointestinal symptoms, holistic care, PROMS

Focus on symptoms and quality of life using PROMS: GI-NET21 and GI symptom rating scales

GI symptom scores significantly lower in the new service (GINET21 $p=0.006$ GSRS $p=0.004$)

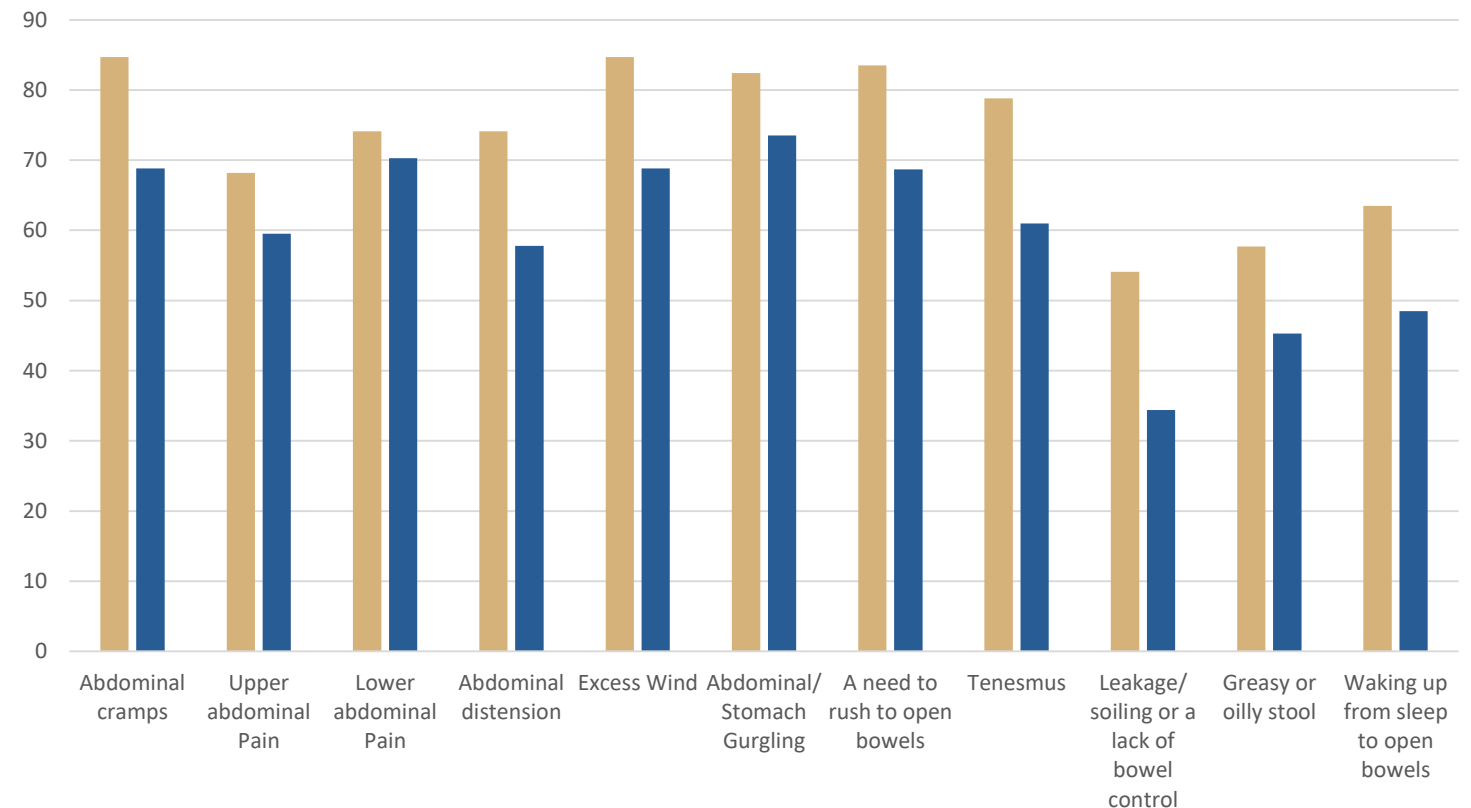
Reduction in all symptom categories with GI symptom impact from 7/10 to 5/10

Regular engagement with patient group meetings in Cardiff and Swansea with psychology access

Patient education, talks, Q&A and drop-in sessions

93% felt their symptoms were being addressed

GI symptoms experienced by Patients



Summary



This is the first time that coordinated specialist care for people with Neuroendocrine Tumours has been commissioned on a national level in the United Kingdom

Despite an extremely negative public image with a resulting poor service historically, it is still possible to 'turn round' the situation with genuine, honest and transparent engagement with the patient groups over a wide geographic area.



Through co-production and an iterative method of developing a service with repeated feedback from the patient voice, a successful service which is valued by patients is achievable.

In addition to the complexity of the disease (which is heterogeneous), this initiative has involved complex pathways across financially independent organisations and cancer networks.





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