

Inquiry into the progress made to date on implementing
the Welsh Government's Cancer Delivery Plan

Evidence from NET Patient Foundation - CDP 40

Response to the inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan.

Neuroendocrine tumours represent a complex group of tumours that develop from cells in the digestive or respiratory tracts, as well as in a wide range of endocrine organs (pancreas, adrenal, thyroid, pituitary) and other rare sites (ovary, thymus, skin). In some cases the disease is familial and may affect several organs in the same individual; multiple endocrine neoplasia (MEN).

Data on the prevalence of these tumours is sparse, particularly in the UK. However, taken together (based on US data) NETs are more prevalent than gastric and pancreatic cancers combined. Approximately 3,000 people a year develop Neuroendocrine Tumours (NETs) in the UK and the rate appears to be increasing.

NETs have a wide spectrum of clinical behaviours; the majority are relatively indolent, slow growing tumours which behave like "cancer in slow motion", whilst a small proportion behave much more aggressively, resembling high grade, small cell carcinoma.

Many tumours also secrete hormones that give rise to a number of clinical syndromes which can have severe effects that may lead to disabling symptoms or have long term metabolic and systemic consequences.

The most well known of these is 'carcinoid syndrome', formerly NETs were often termed carcinoid tumours.

However, because many patients survive many years, by prevalence it is now the 4th commonest GI tumour.

There is a strong patient support group in South Wales who have been very proactive in trying to improve services for NET patients in Wales. Some of the issues that they are faced with and that need to be addressed through the Cancer Delivery Plan are predominately based on equality in cancer care. The NET patient population need to be receiving the same quality of care and access to expertise, including the need for a dedicated specialist nurse and access to all treatment options available in England to NET patients.

It is difficult to perceive how Wales can achieve comparable mortality and survival rates with the best in Europe when NETs are "under the radar" in Wales.

A small study of 200 patients showed that there was a 61% misdiagnosis rate, with diagnosis still taking up to 3 years and beyond, leading to patients presenting with

metastatic disease. We are currently running a survey in Wales and would be happy to share those results with you once they have been collated.

The Welsh Cancer Delivery Plan needs to recognise NETs as a group of malignancies and the ideals that are mentioned in the plan such as the equality for all, early detection, meeting people's need and information, all fall short where this group of patients are concerned.

Recommendations:

Working with the already formed 'European Centres of Excellence' may be a first step, and forming partnerships to help ensure access to treatments that are largely funded in England, through the CDF.

Appointing a dedicated specialist nurse in NETs is essential ensuring that the educational needs are met. There is a European NET nursing group that can provide many tools.

Utilising information for patients that is freely available and ensuring that it is present in each hospital. Preliminary data from a NET patient quality of life survey stated, 'by far the issue of greatest concern to patients related to confidence in their diagnosis and treatment, and the adequacy of the information that they received about their condition'. There is a wealth of information including patient booklets, diaries, wallet cards and DVDs, that can be distributed.

Ensuring a strong referral pathway is in place so that patients are seen by specialists with knowledge and expertise, and who have treated many patients and who are active within the European and UK NET communities. This ensures the right treatment pathway, access to clinical trials and access to support for the medical, nursing and patient community. Research has identified that a number of bowel cancers are in fact NETs and "rapid diagnosis" and "earlier diagnosis" would lead to better outcomes for patients.

The NET Patient Foundation is the only charity in the UK & Ireland dedicated to providing support and information to people affected by neuroendocrine cancers.

The NET Patient Foundation was formed at the start of 2006 and has Charity Commission status.

The Foundation has the following aims:

- To provide support, education and information to anyone affected by neuroendocrine cancers.
- To advocate for neuroendocrine cancer patients so they may achieve the best possible outcomes.
- To encourage standardised care for all NET cancer patients.
- To provide community supportive care to patients and their carers or family members.
- To raise awareness of NET cancers throughout the UK.
- To raise funds for clinical and translational research projects.