One-Size Fits No-One: How can we improve the impact and outcomes for patients who follow a less common pathway?

References


**FOREWORD**

The NET Patient Foundation (NPF) welcomed the Cancer Task Force’s 5-year strategy for England, *Achieving World-Class Cancer Outcomes*, when it was published in July 2015 and the subsequent commitment from the National Cancer Director, Cally Palmer, in May this year, to oversee implementation of the strategy.

This national cancer strategy presents a tangible and realistic starting point for improvement, but focuses largely on the well-known and better catered for cancers that already have well-established pathways. Too often in the strategy, as in life, those that follow a less common pathway (such as the neuroendocrine cancer patients we represent) are overlooked, however unintentional that may be. Today we have responded to that vacuum with the Chapter 10 Report. It is also important to note that whilst this report centres on the cancer strategy for England, the recommendations stand for Wales, Scotland and Northern Ireland too, as do the challenges faced by neuroendocrine tumour (NET) patients in these areas.

As patients, carers, healthcare professionals or activists, we find ourselves in exceptional times; with a £30 billion NHS deficit and annual new cancer cases expected to rise to 300,000 by 2020.1 The fact remains that every one of these patients deserves and expects the best standard of care that a modern healthcare system can offer. To stand any hope of meeting this expectation, we have no alternative but to change our approach for cancer patients who follow a less common pathway too.

In these exceptional times, we may see some exceptional changes and we wait eagerly for the results and learnings from the Cancer Vanguard and to see how implementation of the strategy begins to improve outcomes for patients. However, as the national cancer strategy itself points out, our role as patients and the public is to provide external accountability by championing the need for higher standards and better delivery of cancer care. Whilst considerable progress has been made in raising the needs of rare and less common cancers up the agenda, there is room for so much more – and not necessarily more funding but more focus, more effort and more collaboration.

Rare and less common cancers now account for almost half of all new diagnoses2 and cancerous NETs are the second most common gastrointestinal cancers after bowel cancer.2

We know these patients do not always get the long-term support, information and specialist referrals they need and we must do more to address these challenges.

This year the NPF is ten years old and we are immensely proud of what we have achieved to-date. It is a significant milestone for us as an organisation and for the patients past, present and future that we support. In recognition of this milestone and world NET Cancer Day we have released the ‘Chapter 10 Report’ in which we pose the question ‘Where is Chapter 10?’ of the national cancer strategy. Where are the recommendations that specifically look at improving the impact and outcomes for patients who follow a less common cancer pathway? Where are the recommendations that will improve NET patient outcomes?

We are small, but mighty, and we hope we will be heard but most importantly that we will be listened to, alongside the incredible experts in the field of this unusual, less common and tragically in the majority of patients, incurable cancer.4

Catherine Bouvier, Co-Founder and CEO of NET Patient Foundation

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**Introduction**

**Ten Years On: Protecting a World Class Service**

NETs occur in the cells of the neuroendocrine system, which regulate critical bodily functions such as breathing and eating. As neuroendocrine cells exist throughout the body, cancerous NETs can arise in many different areas but are commonly found in the digestive or respiratory tracts.

NETs can affect people of all ages and over 4,000 NETs are diagnosed each year in England (which equates to around 8 per 100,000 people) and incidence is rising.5

NETs are complex and unpredictable, and 15 years ago the UK was a relative backwater for NET management but, thanks to the incredible efforts of some exceptional clinicians and nurses, we are now one of the leading countries in the world for NET patient care with the largest number of European NET Centres of Excellence – 10 in total. The UK’s global status, however, is under threat in light of recent funding cuts to support radiopharmaceutical treatments and the urgent need to commission specialist services. We also face significant barriers regarding awareness, healthcare professional (HCP) education and funding for research.

**Improving Impact and Outcomes for Patients Who Follow A Less Common Pathway**

The national cancer strategy for England has provided a solid foundation and seized the momentum for change within the 5-Year Forward View. However, it is undeniably heavily focused on the common cancer pathways and how to improve outcomes more broadly for these patients. Whilst we welcome and acknowledge the recognition that rare and less common cancers have in the existing strategy, to secure better outcomes for those cancers we must go further to support these diverse patients.

We believe the strategy needs a razor sharp focus on this area with further specific recommendations.

This report outlines some of the challenges, perceived gaps and potential recommendations that a ‘Chapter 10’ could deliver. Whilst our examples are NET specific, we believe the principles are aligned to the needs of the less common cancer patient more generally and our hope is that this report will encourage the recognition and improvement of care for all patients following a less common pathway.

**This report outlines some of the challenges, perceived gaps and potential recommendations that a ‘Chapter 10’ could deliver**

Most significantly, the report makes recommendations around greater collaboration with experts and expert groups that represent and care for these patients – an important objective that could vastly improve the impact and outcomes for rare or less common cancers. Whilst we know this is happening in certain circumstances, and some may argue the voice of the cancer community has been listened to and had considerable impact over the last 10 years, there are still very clear examples where the appropriate expert advice for rare or less common cancers is not being requested let alone considered.

There were 96 Recommendations made in the national cancer strategy, two of which specifically related to rarer cancers – NET Patient Foundation requests that a tenth chapter be considered for inclusion supporting the aims of an additional four recommendations to:

- **Increase efforts to capture incidence and experience data for rare and less common cancers, specifically cancerous NETs**
- **Learn from and protect existing rare and less common cancer pathways and services, specifically the NET Centres of Excellence**
- **Implement service specifications and commission services for rare and less common cancers – for example in cancerous NETs where a service specification was created in 2013 and is yet to be implemented**
- **Ensure any cancer taskforce has mandatory inclusion of the relevant tumour specific expert input (and where appropriate patient organisations) for example NETs, to feed into national decision-making**

These recommendations are outlined in greater detail below (NET Patient Foundation Chapter 10 Recommendations: 97–100) and have been aligned to the relevant strategic priorities of the national cancer strategy.
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Treatment and Care

NET patients are less likely to respond positively to questions about their treatment and care than other cancer patients including whether they think their views are taken into account and whether they feel involved in decision-making.

The majority of respondents reported a positive overall experience of their NET care with 83% reporting that it was either excellent (47%) or very good (36%). However, the 2014 CPES found that in all types of cancers 89% of respondents rated their overall experience of care as excellent (57%) or very good (32%). Again, this is a significant finding, suggesting that NET patients are overall less happy with the care they receive from NHS services.

The CPES is widely recognised as a key tool in tackling variation of experience. The national cancer strategy itself points out that patients with rarer cancers report a less satisfactory experience, so we must make sure as many rare and less common cancers as possible are represented in the national survey. These patients follow a less common pathway and therefore the nuances of these differences may well be the very things that determine between good and bad experiences.

Data Gathering

Chapter 1 of the national cancer strategy looks at the current landscape of cancer in England and Chapter 2 goes on to consider how best to capture patient experience and metrics as a key instrument for service improvement.

More must be done centrally to capture accurate incidence and patient experience data in rare and less common cancers or as is suggested in the national cancer strategy, to link up existing data sets. We cannot hope to make significant progress in cancer care for these patients if we do not know they exist (in relation to capturing accurate incidence data) or what their experiences are in their specific treatment pathway.

NET Patient Experience

NETs were not included in the 2014 or 2015 CPES due in part to limitations around accuracy of coding and because NETs follow a different pathway; the standardised national CPES does not 'fit' this patient population, again highlighting the deficit in capturing patient experiences for rarer or less common cancers.

Where rare or less common cancer patient experience has been captured in the CPES, we know their experience is significantly less positive than other cancer patients.
Layla’s Story

In 2002 Layla started to experience extreme stomach pain and flushing but these remained unexplained and undiagnosed despite various tests. She was given codeine to manage the pain but when her local pharmacist established she was taking three times the recommended dose and still having no pain relief Layla was urgently advised to get a second opinion. At the same time Layla was trying for a baby through IVF and remained focused on the IVF rather than getting to the bottom of her stomach issues. When Layla fell pregnant the pains ceased and she had a trouble free pregnancy. However, after the birth of her son Hadley, Layla became very unwell. She lost three stone in a couple of months and was even accused of anorexia by concerned family members.

When her son was four months old Layla was passing out on a daily basis and after being admitted to hospital in an emergency, after collapsing once more, she was finally given an MRI scan. The scan revealed ‘a lump’ in her intestine after being admitted to hospital in an emergency, after collapsing once more, she was finally given an MRI scan. The scan revealed ‘a lump’ in her intestine after being admitted to hospital in an emergency, after collapsing once more, she was finally given an MRI scan. The scan revealed ‘a lump’ in her intestine after being admitted to hospital in an emergency, after collapsing once more, she was finally given an MRI scan. The scan revealed ‘a lump’ in her intestine. Layla was told she had cancerous tumours in her small bowel and that it had spread to her liver. Layla had some very ‘dark days’ after that diagnosis but she had her son to consider and was determined to focus on fighting her cancerous NETs. The physical strain has certainly been hard but Layla also stresses the psychological impact her NETs have had. She says people don’t quite understand her cancer because some days she can almost forget she’s ill and continue working and living a relatively normal life, which means she almost feels like a fraud! However, the nature of NETs means they are unpredictable, difficult to treat and often incurable when diagnosed (the majority of patients are at an advanced stage at diagnosis). In this way it has taken over her life.

Layla feels a lot of patients aren’t told the facts when diagnosed, they aren’t told that their cancer is incurable and will ultimately kill them particularly as no-one can really predict how long a patient may live with cancerous NETs. Even though it is ‘terminal’ -- survival rates can vary hugely.

Eight years on and Layla has continued her fight to this day, after seven separate surgeries including a 12-hour stomach operation – it has been an epic battle but she remains focused and positive.

Patient Testimonial – Layla Stephen (NET patient)

Background

Layla is 41 years old and a working mother. She lives in Hampshire with her son Hadley (8) and her husband. Layla works as a Client Development Manager in finance and also runs her own regional NET support and fundraising charity, PLANETS, based at Southampton hospital where she is a patient at the NET Centre of Excellence.

The care my husband received at the specialist NET centre was worlds apart from what we experienced at a non-specialist hospital. At the specialist centre there was a confidence and expertise that made us feel we had access to an equal level of expertise as those following a more common pathway.

My husband lived for 15 years with his neuroendocrine cancer and was able to work and continue a relatively normal life because he rode a wave of new treatments trialled at a Centre of Excellence with the expertise and competence to do so.

Helen Parker, wife of Philippe Parker, a NET patient

Recommendation 98

The UK NET Centres of Excellence are an exemplar to other cancer types. We should protect this positive area of excellence in our system and where appropriate learn from it.

World-Class Care

Chapter 3 explores the key principles that underpin the national cancer strategy including external accountability and championing the need for higher standards and better delivery. Indeed, as we strive for ‘world-class’ cancer outcomes, we should recognise and learn from examples of world-class care in our own system.

It is not often that we can genuinely say in the UK that we are light years ahead in terms of cancer care and even the empy of countries such as the United States – but in cancerous NET care this is the case. Over the last 10 years a dedicated community of specialist clinicians have built their knowledge, skills and experience to catapult themselves into world-class standing and this should be celebrated, shared and most importantly protected.

Our UK NET experts have proven worldwide expertise, authoring a number of global publications and delivering internationally acknowledged research portfolio.

This ecosystem of excellence has grown in spite of the challenges faced around commissioning, education and research. We not only need to fiercely protect this specialist service, but we should be learning from it and sharing these insights across other cancer types, certainly other rare or less common cancers.

Access to Treatment

The NET Centres of Excellence in England form part of a wider European network of excellence. In 2007, the European Neuroendocrine Tumour Society (ENETS) Executive Committee formed a task force to investigate the feasibility of establishing Centres of Excellence for treating NETs. A network of centres, they reasoned, would allow NET patients to seek specialists who could best treat them, and would also unify the care and research being conducted in the NET field across Europe. Achieving ‘Centre of Excellence’ certification from ENETS has required huge dedicated efforts by our 10 centres in England, not least securing NHS Trust support, appropriate training and auditing, research, MDT synchronisation, specialist services and running extra clinics. These Centres of Excellence currently face new threats in relation to funding. NET Patient Foundation is challenging a recent decision to cut funding for specialist treatment at these centres. The decision to remove funding for Peptide Receptor Radionuclide Therapy (PRRT), the current standard of care in Europe, significantly impacts the UK’s position as a world leader in the treatment of NETs and, most importantly, denies life extending treatment for patients.

Currently, PRRT is funded in the devolved nations (Wales, Scotland and N. Ireland) but was de-listed from the Cancer Drugs Fund (CDF) in 2015 along with several other treatments for rare or less common cancers. We eagerly await the NICE Multi-Technology Appraisal (MTA) that will look at PRRT and approving national funding for this treatment. This is anticipated in July 2017, but until then we have a deeply inequitable situation for those patients who may fall between the gap.

Until recently we have been able to deliver world-leading care for our NET patients, sadly this has been put at risk by the Cancer Drugs Fund (CDF) panel demonstrating an inadequate understanding of the disease and current treatments. There have been several decisions taken in isolation by the CDF over the last two years which together have deprived the majority of patients with advanced neuroendocrine cancers from access to some of the most potent treatments including radio embolisation, PRRT and everolimus. In particular, it is hard to see how the panel of health care experts who made the assessment on PRRT and subsequently de-listed it from the CDF have comparable expertise to the combined authority of the entire specialist clinical NET community who have used this treatment as the standard of care for the last 20 years. We now have to hope that NICE will make the appropriate decision to grant patients access to the European standard of care for metastatic NETs.

Nail Pearce, Consultant Surgeon, Southampton ENET Centre of Excellence

Strategic priority: make the necessary investments required to deliver a modern, high-quality service
Recommendation 99
Service specifications for complex cancers should be commissioned including implementing the existing NET Service Specification.

Commissioning for NETs
Whilst the national cancer strategy proposes a national commissioning policy for rare cancers (500 or fewer cases per annum), and national or regional MDT where appropriate, we can assume there remains a significant number of patients with rare or less common cancers who will not fall into this bracket. They will be reliant on local commissioning and it is essential that complex cancers are commissioned and the patient pathway optimised for these often hard to treat patients.

NET patients often have to live with their cancer and associated treatment for prolonged periods of time and for the vast majority of patients their cancer is incurable at diagnosis. Up to 60% of cancerous NET patients are diagnosed at an advanced stage.4

An Unpredictable Cancer
The unpredictable nature of cancerous NETs presents a significant physical and emotional challenge for patients and their families, over what can be many years. The national cancer strategy identified the importance of stratified care for patients living with and beyond cancer and published further guidance for Commissioners and Strategic Clinical Networks in April this year. Again, patients with NETs don’t follow the common algorithm of remission, palliative or end-of-life care. Patients with neuroendocrine cancer follow a totally unpredictable path of inactive tumour growth for maybe several years followed by accelerated growth and possibly repeated surgery or other aggressive treatment. The psychological impact of what patients describe as ‘a new diagnosis every time’ is enormous. The national cancer strategy has proposed a primary focus on breast, colorectal and prostate cancer for the ‘Recovery Package’ for patients living with cancer and, whilst new initiatives will often need such focus for implementation, again rare and less common cancers must be considered when phasing in stratified care for patients living long-term with cancer.

In the last 20 years we have moved beyond the umbrella term ‘cancer’, some might even say beyond cancer type to a highly individualised ‘tumour type’ approach. Even more so with rare and less common cancers. This report asks that the national cancer strategy go further in terms of the specifics of how we approach rare and less common cancers, and this can only be done through consultation with those who hold the specific knowledge and experience of these less common pathways.

Recommendation 100
Greater impetus is needed for genuine collaboration and effort to seek input from the appropriate expert and patient organisation in national strategy and decision-making. Any cancer taskforce should ensure the mandatory inclusion of the relevant tumour specific experts, including NETs (and where appropriate expert patient organisation) that can look at the less common cancer patient pathway and feed into any centralised consultation process.

Funding for Treatment
The decision to remove PRRT from the CDF was one which was vociferously rejected by the NET cancer community as a backwards leap in terms of cancer care – because in mind the treatment is the European standard of care. Whilst we respect and are involved in the Multiple Technology Appraisal (MTA) process to get this treatment access back, we are still having to urgently push for a specific NET expert to sit on the panel of this MTA. As always, expert evidence will be submitted, but we firmly believe this is too complex a cancer and too important a decision for there not to be a NET expert on the panel.

The NICEL guideline (NG12) published in 2015 for GP referrals for suspected cancers is an example of a missed opportunity for this group of patients. The guideline supports referral decision-making regarding symptoms and signs that warrant investigation for suspected cancer. It covers several less common tumour types including those with a far lower incidence than neuroendocrine cancer. This guideline can only be invaluable for identifying cancerous NETs because we know that cancerous NETs can be difficult to diagnose due to symptoms that can be somewhat vague or attributed to more common problems such as irritable bowel syndrome (IBS), Crohn’s disease, peptic ulcer disease, gastritis, asthma, blood glucose problems, menopause and blood pressure problems. Some NETs produce abnormally large amounts of hormones, these NETs have a related syndrome, the most common of which is called ‘carcinoid syndrome’. We believe capturing some of the more common carcinoid syndrome symptoms in this guideline could have significantly helped earlier NET diagnosis. We need to avoid missed opportunities like this through greater collaboration and considering the best ‘fail-safe’ method of ensuring the relevant expert groups and clinicians are called upon, such as a cancer ‘index’ for complex or rare cancers. This could support both policy makers as well as larger umbrella cancer organisations. We may see an increased role for this in the roll-out of multi-disciplinary diagnostic centres (Recommendation 21), whereby tumour specific experts of rare or less common cancers can feed into pathway planning.

Chapter 10 Report

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Chapter 10 Report
SUMMARY

This Report is not about trying to fit all cancers into one pathway but standing back and saying, whilst we can write a strategy for most that will be appropriate and impactful, we need to look at other treatment pathways and specialist areas for those cancers that don’t fit. Those that may not even include traditional pillars of treatment like radiotherapy and chemotherapy, for instance, or those that can be totally unpredictable in terms of proliferation and growth rate – steady and slow one minute and then suddenly terrifyingly fast, like NETs.

It is the individualised nature of the rare and less common cancers that mean we must ensure there is greater tumour specific input into national decision-making and policy, even if only for a small proportion of patients and if represented this input should be weighted and considered accordingly.

At NET Patient Foundation, we understand that proportionally we are a small group and that is why this Report is asking for proportional input to be recognised, not simply left out.

Most importantly, we do not believe our recommendations are necessarily costly, they are about fair representation and listening to the expertise that exists in this highly complex cancer.

With this report we have asked the question ‘Where is Chapter 10?’ to draw attention to the needs of NET patients. If there is consensus that indeed ‘one-size fits no-one’, then we hope this Report can support a refocus, within the framework of the national policy, that genuinely strives towards world-class cancer outcomes for everyone.

The NET Patient Foundation is the only charity in the UK dedicated to providing support and information to people affected by neuroendocrine cancers. For the last 10 years, NET Patient Foundation has been providing expert support and services to patients at diagnosis and throughout treatment.

NPF is focused on bridging the gap between hospital and home for patients with cancerous NETs and runs a dedicated specialist nurse-led helpline to support patients. It also runs 26 support groups around the UK and national education days each year to support patients, supporters and families at diagnosis and throughout treatment. The tailored information provided by the NPF is critical to help patients manage their cancer and identify the specialist care they need.

As well as providing supportive care for patients and carers living with cancerous NETs, the NPF also funds vital clinical research in the UK and provides education for HCPs.

More About NET Patient Foundation

We will continue to strive to improve awareness, increase support structures, vastly improve healthcare education in this medical area and raise vital funds for research.

NET Patient Foundation is proud to be part of the International Neuroendocrine Cancer Alliance (INCA) and to support Worldwide NET Cancer Awareness Day (10th November 2016).

www.netcancerday.org