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One-Size Fits No-One:

How can we improve the impact and outcomes for patients who follow a less common pathway?

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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.³

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

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.^{3,5}

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.

Where is Chapter 10?

Strategic priority:

establish patient experience as being on a par with clinical effectiveness and safety

Recommendation 97

NHS England should work with specialist cancer charities and other tumour specific experts to ensure accurate data gathering, regarding incidence and patient experience for patients with rare or less common cancers. In particular, looking to either widen the reach of the 2017 National Cancer Patient Experience Survey (CPES) to include a broader range of treatment pathways and members of the multidisciplinary team (as NET patients may not necessarily be seen by an oncologist) or create an additional CPES for NET patients and those following a less common pathway.

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.

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While there is a lot in the national cancer strategy to welcome, there is much more that can be done to bring about improvements for the forms and types of cancer that don't fit the mainstream norm that has been identified for common cancers. The NET Patient Foundation 'Chapter 10 Report' clearly highlights why and how some of the proposed cancer strategies need further refinement and targeting (and, in some cases, wholesale change) if they are to help people affected by neuroendocrine tumours (NETs). There are parallels between NETS and lymphomas (and indeed other haematological cancers), where the complexity of these cancers and their numerous subtypes, presentations, diagnoses and prognoses, don't fit the standard cancer model of prevention, early diagnosis, curative treatment and hopefully recovery.

Jonathan Pearce,
Chair, Cancer52

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Historically, the national reporting and registering of NETs has been patchy and inaccurate, primarily due to limitations of the coding system for registering tumour types. Identifying rarer cancer patients in the first place and, in the case of NETs, coding these tumours accurately, presents a significant challenge regarding representation in the CPES. For NETs, some significant progress has been made in this area. The National Cancer Registration and Analysis Service (NCRAS) at Public Health England has recently undertaken a piece of work in collaboration with NET Patient Foundation to improve the coding system for cancerous NETs, which is a big step in the right direction. This work has had a significant amount of funding support from NET Patient Foundation and uncovered a wealth of information about NETs. After a historical dearth of comprehensive regional incidence data, the latest evidence suggests that neuroendocrine cancer affects far more patients in England (8 per 100,000) than we originally believed,⁵ which is in line with the global trend of an increase in incidence.³

In 2015, considering the lack of NET patient representation in the CPES, NET Patient Foundation commissioned its own Patient Experience Survey. Due to the difficulty in identifying NET patients, samples were drawn

NET patients are less likely to respond positively to questions about their treatment and care than other cancer patients

by working directly with seven NHS Trusts in England providing specialist NET treatment. There was a good response rate and we were able to gather a statistically valid sample (996 responses). The survey results provided important data, covering a range of themes related to the care and treatment of neuroendocrine cancer patients.

The NET Patient Survey Report compared the results to the 2014 CPES, and there are some stark differences between the experiences of NET patients compared to all cancer patients who completed the 2014 CPES. Most notably around diagnosis, information and treatment.⁶

Diagnosis^{6,7}

It takes far longer for NET patients to be diagnosed and they will see their GP more often; will be misdiagnosed or treated for another condition; and their condition is more likely to get worse before treatment starts.

- **NET patients** have to see their GP far more often than other cancer patients before they are referred on to hospital – 44% of NET patients see their GP only once or twice before referral; whereas for other cancer patients this is 75%. Just over a third of NET patients saw their GP more than five times (35%) before referral
- **Just over half** of NET patients (58%) see a hospital doctor within three months of noticing that something may be wrong; compared to 78% of other cancer patients
- **NET patients are less likely** to think they are told they had cancer sensitively – 74%, compared to 84% of all cancer patients
- **More NET patients** said their health got worse between first seeing their GP and starting cancer treatment (38%) compared to other cancer types (20%)

There are significant challenges and delays in diagnosis in the UK and indeed globally. This is in part due to the varied nature of symptoms, which are often the same as more common conditions. However, there is also a distinct need for greater awareness and education specifically in the medical community.

In a global survey of NET patients (including UK respondents), almost half of respondents reported not receiving NET as the first diagnosis and they also reported seeing an average of six HCPs prior to their NET diagnosis.⁸

Information and Explanations^{6,7}

NET patients are less likely to receive written information in all stages of their treatment and care, whether at diagnosis or during tests. They are also far less likely to understand the explanations they are given about all aspects of their cancer treatment.

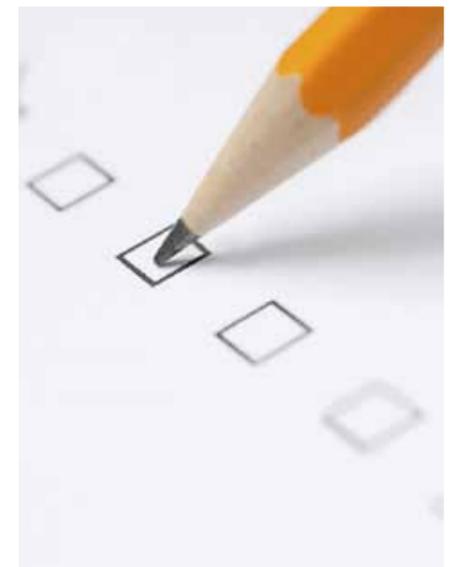
- **Only half** of NET patients said they were given written information about all of their tests – compared to 91% of all cancer patients who say they received written information
- **Less than half** (47%) of NET patients said they received written information about their type of cancer that is easy to understand; compared to 72% of other cancer patients
- **Far fewer** NET patients said they understood the explanation of what was wrong with them (47%) than other cancer patients (73%)

Treatment and Care^{6,7}

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.



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.



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 and after further investigation, just a week before her son's first Christmas, 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.

“*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 experience 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

Strategic priority:

make the necessary investments required to deliver a modern, high-quality service

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 envy 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 an 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.*”

Neil Pearce, Consultant Surgeon,
Southampton ENET Centre
of Excellence

Strategic priority:

ensure commissioning, provision and accountability processes are fit-for-purpose

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.

In due course we will see the learnings from the NHS Vanguard (sites selected by NHS England to test the new care model programmes) rolled out across the patient pathway and the Cancer Alliances (recommended sub-regional organisational structure comprising key partners) flex their new powers to implement changes to clinical quality and outcomes. We urge clinical leaders implementing change to consider the less common pathways and how we can improve outcomes for these patients as well as how we can protect and learn from positive pathway examples. In the case of NETs, a Service Specification has been in existence since 2013 but is yet to be rolled out and commissioned. This has been delayed to 2017/18 at the earliest with no reasons specified. This highlights that in some cases we are not looking at 're-design' or detailed workstreams but rather following through with a greater focus and willingness to improve outcomes for these patients.

Appropriate Referrals

A significant challenge for cancerous NETs is appropriate referrals to regional Centres of Excellence, which for many patients is still not the case. Patients with these complex tumours need to be seen by experts with the skills, knowledge and most up-to-date treatment expertise. Earlier NET specialist referrals and earlier access to appropriate treatment options can significantly improve outcomes for NET 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.

“*The availability of expert medical professionals for NET patients is a critical factor. Treatment usually involves a range of specialists given that tumours can form in several parts of the neuroendocrine system, which is why access to well-coordinated multi-disciplinary specialist care is essential. Too often we see patients in our Centre of Excellence for whom the prognosis would have been very different if they had been discussed in our tertiary multi-disciplinary meeting sooner.*”

Professor John Ramage, Lead Clinician, King's Health Partners, Kent and Hampshire Hospitals NET Centre of Excellence, and UKINETS Chair

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.

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.

Rare and less common cancers have been well represented on the Independent National Cancer Advisory Group by Cancer52, a coalition of more than 90 cancer charities (including NET Patient Foundation) representing rare and less common cancers and Cancer52 provided a comprehensive briefing on the implementation of the strategy. <http://www.cancer52.org.uk/wp-content/uploads/2014/09/Cancer52-Briefing-on-Cancer-Strategy-FINAL.pdf>

NET Patient Foundation is the only charity in the UK dedicated to providing support and information to people affected by neuroendocrine cancers and so we are well placed to offer the relevant insight and expertise into how these patients are cared for, alongside the expert clinicians and nurses in the NET community. Yet we find ourselves still having to fight for representation and for our voices to be heard in national decision-making that affects NET patients.

The issue was also raised at a European level in a series of policy recommendations from a European Parliamentary roundtable in 2015 urging Member States lacking a focused policy on NETs to consult specialists and utilise recommendations for best practices drafted by those specialists. The report also coined the phrase 'nothing about us without us' to highlight the need for organisations representing patients with

NETs to be appropriately consulted on all policy and legislation that will affect NET patients.

The NICE Guideline (NG12) published in 2015 for GP referrals for suspected cancers is an example of a missed opportunity for NET 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 could 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 supported 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 rarer 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.

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 – bearing 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.

“*There's already clear recognition in the cancer strategy that one-size fits no-one – and we were delighted that Cancer52 had both a seat on the Cancer Taskforce that wrote the strategy and now on the Independent National Cancer Advisory Group (NCAG) to represent rare and less common cancers on these key groups.*”

It's a significant role and we would welcome the opportunity to improve our input through working on some of the suggestions in this NET Patient Foundation report that would help us better resource and support the focus on rare and less common cancers within delivery of the cancer strategy.

We are aware of some great pools of expertise within our network like the NET Patient Foundation in specific cancer areas and will seek to find ways to bring more of this expertise to the table.

Cancer52

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.

More About NET Patient Foundation

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.

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



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