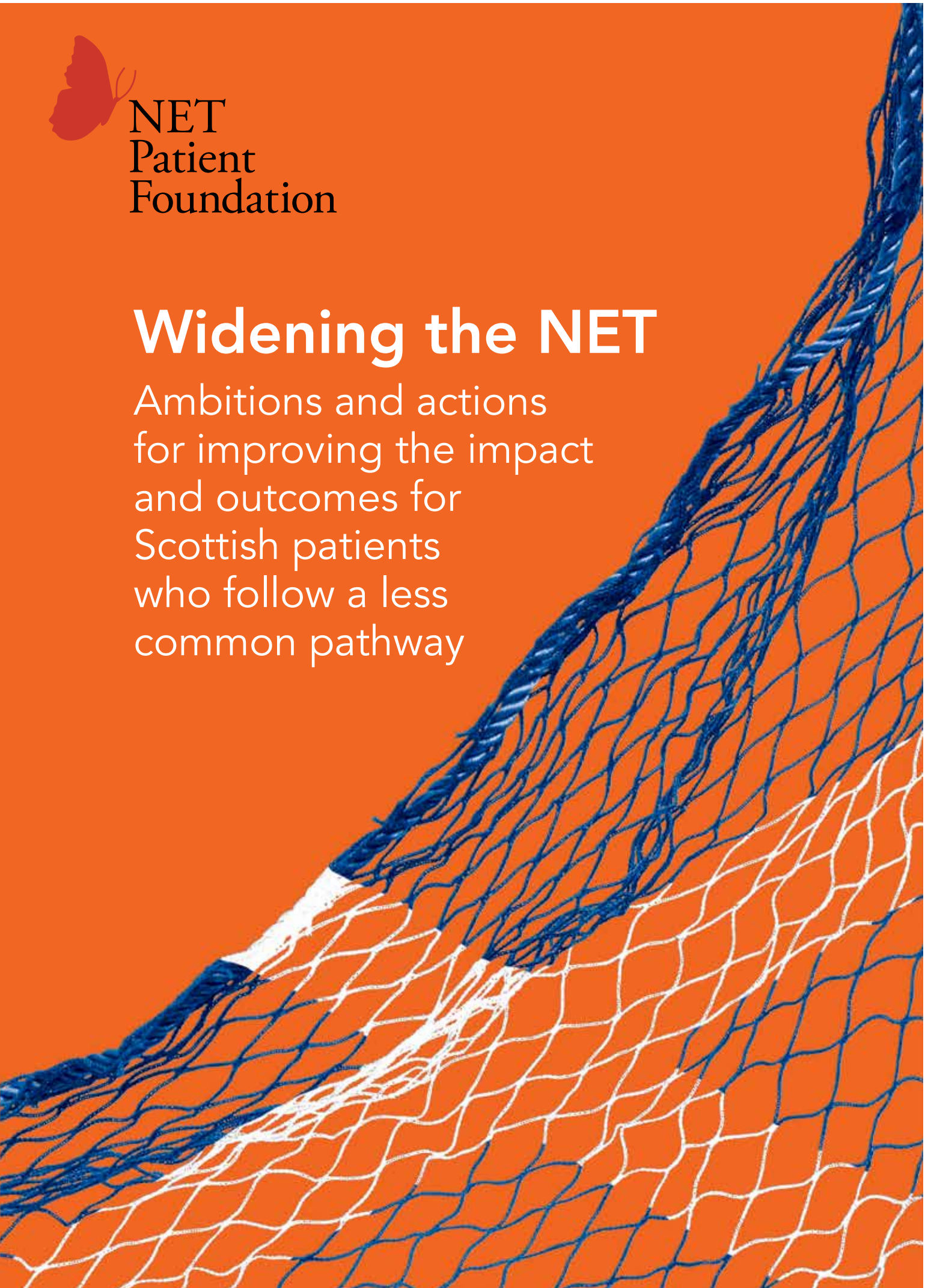




NET
Patient
Foundation

Widening the NET

Ambitions and actions
for improving the impact
and outcomes for
Scottish patients
who follow a less
common pathway



FOREWORD

Since launching NET Patient Foundation over a decade ago, the outlook for patients in the UK with a Neuroendocrine Tumour (NET) has improved significantly. There are more specialists, a greater range of treatments and a better overall understanding. I've been fortunate to witness the building of a community of health professionals, patients, supporters and charities with one key goal in common – to improve outcomes for those who follow a less common cancer pathway.

However, we still hear stories every day from patients who have had to wait years to receive a correct diagnosis, haven't had access to specialist support, or have felt isolated and confused. NETs are complex to understand and treat and that is why we must focus our efforts on ensuring that every patient, no matter what type of NET they have or how unique their pathway, receives the same level of care.

In 2016, we developed the 'Chapter 10' report, which scrutinised the national cancer strategy for England and highlighted areas where those

with rare or less common cancers, NETs in particular, were being overlooked.¹

In 2017 we have focused our attention specifically on Scotland to explore the current situation for patients with a malignant NET and identify if any improvements could be made.

Although the two largest cancer centres in the central belt in Edinburgh and Glasgow cover around 80% of the population – those who live further away may struggle to access this and the multidisciplinary approach pioneered in the West of Scotland may not be so easy to implement elsewhere. Additionally, patients in some areas of Scotland may find it difficult to access peer-to-peer support groups or specialist NET nurses. This may be particularly true for patients in rural or hard-to-reach areas such as the islands.

We were pleased to read the 'ambitions' and 'actions' outlined by the Scottish Cancer Strategy

published in 2016.² However, as with the English strategy, we saw very little focus on those following a less common pathway and no mention of NETs at all. Therefore, we call upon the strategy to be more ambitious yet and have outlined our own key '**ambitions**', and corresponding '**actions**', with the specific aim of improving the experience and outcomes of Scottish patients with malignant NETs.

We hope this report will keep NETs firmly on the agenda so that every NET patient in Scotland has access to the same standard of care and support as those with more established and well-recognised cancer types.



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

During my time working as a consultant clinical oncologist in Scotland there have been some considerable achievements, particularly in recent years. Awareness of NETs has improved, not just among healthcare professionals but among those making policy decisions and we have started to see that filtering through into everyday practice.

Patients now have access to a greater range of treatment options across Scotland. I've also been able to offer some of my patients the opportunity to take part in clinical research trials. We now have a specialist NET nurse at the Beatson to support patients throughout their pathway and we have some highly-capable consultants all around the country. In short, there is much to celebrate.

However, these changes did not happen overnight and for many years

NETs were simply left out of the equation. They were neither well-understood nor recognised as a cancer type (or subtypes) that needed specific management and treatment.

Even now, there are still many healthcare professionals who are not equipped with the necessary knowledge to recognise and correctly refer a person with a malignant NET and patients are still liable to get lost between specialisms.

A multidisciplinary approach is fundamental to the treatment and ongoing management of NETs and this is something that has been pioneered by the Scottish Neuroendocrine Tumour Group (SCONET), which was set up to share knowledge and standardise the approach to NETs in Scotland. The management guidelines published in 2015 supply a framework for all

healthcare professionals managing NETs and I will be continuing to work with SCONET to encourage their use and provide up-to-date guidance.

My sincere hope is that we can continue to build on the successes we have seen in Scotland so that we can routinely offer our NET patients equal access to timely diagnosis, a multidisciplinary team (MDT), and specialist care, regardless of where they live and which health board they are under. Only then will we really be able to deliver improved outcomes for every NET patient.



Professor Nicholas Reed,
*Consultant Clinical Oncologist,
Beatson Oncology Centre,
Glasgow*

Introduction

Neuroendocrine Tumours and a Snapshot of Scotland

NETs occur in the cells of the neuroendocrine system, which regulates critical bodily functions such as breathing and eating. As neuroendocrine cells exist throughout the body, malignant 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 while some NETs are aggressive, most have a more indolent nature than other types of malignant tumours. This often leads to a significant delay (sometimes up to 7 years), between first appearance of symptoms and a NET diagnosis.³

The annual incidence of NETs is relatively low, but is increasing. Due to the long survival of patients living with NETs, however, the prevalence is amongst the highest of all cancer types, with patients requiring long-term management and support.

Patient numbers

Across Scotland it is estimated that over 150 new NET cases are seen every year.³ The incidence of NETs is on the rise and prevalence is amongst the highest of all cancer types.³ The latest data suggests that approximately nine Scottish people in every 100,000 were diagnosed with a NET in 2015, 2014 and 2013 respectively. This is higher than figures in England which stand at around eight per 100,000 for 2013–2014.⁴

Healthcare infrastructure and geography

Thanks to the efforts of some exceptional clinicians and nurses, the UK is now one of the leading nations for NET patient care with the largest number of “European NET (ENET) Centres of Excellence” – 10 in total, now in place across England.

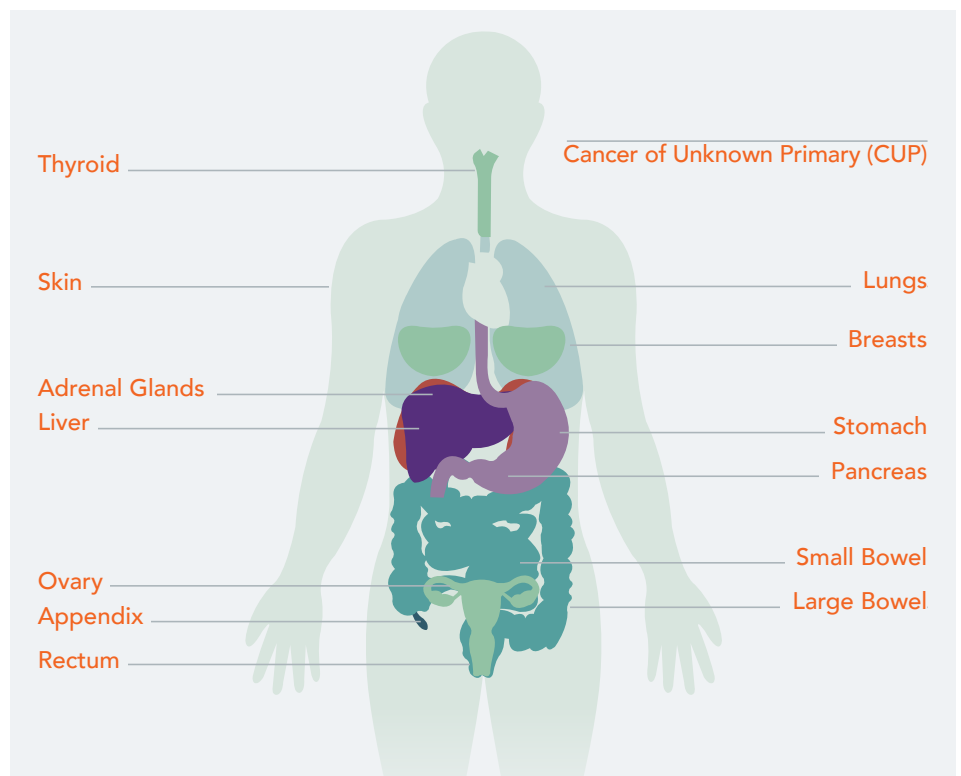
Scotland is yet to establish its own ENET Centre of Excellence but The Beatson West of Scotland Cancer Centre in Glasgow together with the Edinburgh Cancer Centre hopes to

change that. Offering specialist NET expertise, they have ambitions to become Scotland’s first ENET Centre of Excellence with affiliate status for Dundee, Aberdeen and Inverness. Scotland also boasts its own dedicated NET resource in the shape of The Scottish Neuroendocrine Tumour Group (SCONET). SCONET was established in 2011 as a country-wide multidisciplinary group involved in all aspects of the NET patient pathway, with an aim to improve the quality of care for patients with NETs. In 2015 the group produced its *Consensus Guidelines for the Management of Patients with NETs*;³ a useful and well regarded resource for practitioners involved in the care and treatment of patients with NETs in Scotland.

Despite these significant advances, inconsistencies in the care pathway for Scottish NET patients continue to exist. The devolved nature of NHS

Scotland – comprising 15 regional NHS Boards, seven Special NHS Boards and one public health body – combined with the complex nature of NETs, means there is still wide variance in the patient experience depending on where a patient lives and the expertise of the clinicians they encounter.

Additionally, the existence of rural and difficult to reach areas, including the islands (where 20% of Scotland’s population lives), means access to the specialist expertise and services available in a bigger centre is more challenging, especially for those with less common conditions such as NETs. Dedicated resource for NET patients is difficult to justify in these locations given patient numbers but current provision, for example a yearly endocrine clinic run from one of the bigger mainland centres, may leave gaps in ongoing support and care.



NET Patient Foundation Ambition #1:

Building a 'Social NETWORK'

Ensure access to ongoing information, support and peer-to-peer communication for all those affected by malignant NETs in Scotland

Given their complexity, NETs are often difficult to diagnose and are not always correctly handled.⁵ Patients may be treated in relation to the site of the tumour itself, for example, someone with a lung NET may be treated as if they had lung cancer. This can lead to inappropriate management. For example, non-specialists may not be fully aware that in some cases NET patients can live with tumours for some years longer than patients with certain other cancer types.

The situation is further complicated by the fact that different types of NET require their own distinct treatment approaches and many NETs lead to further complications, for example: issues with bowel function, breathing, related syndromes and/or nutrition; that then require the input of other specialisms. Every individual's experience is different and NET patients can face what may seem like a long and lonely pathway.

Alongside physical symptoms patients are also faced with a heavy psychological and social burden, as clinical nurse specialist (CNS) Irene Wotherspoon highlights:

"Some of the common challenges my patients face involve living with very burdensome symptoms such as nausea and loss of appetite; or explosive diarrhoea and incontinence which can be a huge source of embarrassment.

Patients may feel like a fraud or like they don't have a 'real cancer' because they can feel normal for long periods of time and there are no signposts for the outside world such as hair loss.

They can also encounter challenges with work as they are often not well enough to work full time but can do a little. This can make gaining access to income support difficult."

Support groups

Because a person can be living with a NET for a number of years, experiencing varying degrees of symptoms and a range of treatments over the course of this time, the availability of support groups becomes all the more vital.

Both the Ann Edgar Trust in Scotland and NET Patient Foundation (whose remit includes the whole of the UK), are key sources of information and support for patients.

A former teacher with a carcinoid NET and her husband cite the 'amazing support network of the NET Patient Foundation and Ann Edgar Trust' as having made a huge difference. They describe the NET Natter

groups, run by both organisations in collaboration, as being a great opportunity to meet with people in a similar situation. For example, they met a couple at a NET Natter group and have kept in touch with regular email contact and phone calls.

Trevor, had a similarly valuable experience at a NET Natter meeting in Glasgow: "I met other people within my area and had the opportunity to share my experiences with them and learn that they too face similar challenges. Learning that there are other people undergoing similar experiences, and being able to share them, has been a real positive for me."

Glynis, a NET patient living in the West of Scotland, also recently

attended a NET Natter group. Despite initial reservations about going, she found it incredibly useful and will be attending another group soon. She would like to see more of these groups and feels that peer-to-peer support is a key area that could help improve the experience of NET patients in Scotland. She suggested that these could be economically run out of a room in a hospital and felt that patients would wish to attend regardless of the surroundings or facilities.

NET Natter groups are currently run in Glasgow, Edinburgh, Aberdeen and Ayrshire, which are accessible for many patients in Scotland. However, for people who live further away, travelling long distances is not always possible and can be dependent on health

levels and personal circumstances, including finance. Offering funding, or even simply a location, for charities to regularly run these and similar groups in collaboration with specialists from local hospitals could make a substantial difference for patients all around Scotland, particularly in areas that are further north.

Rural and remote areas

Additionally, there are patients in rural areas that are even harder to reach who could feel very isolated. Specialist NET nurse, Irene Wotherspoon, shares her perspective:

"There may be people in rural or outlying areas of Scotland where it may be difficult for patients to access support – particularly in Northern Scotland. For example, I know of a patient in the Outer Hebrides who had to take a 4–5 hour ferry ride, followed by a 4–5 hour train ride only to have his operation cancelled."

Patients may be willing to undertake long journeys to access vital treatment, however, justifying a trip of that length to attend a support group may be more challenging. Although the number of NET patients in outlying areas may not be large, it is important that there are still mechanisms in place to offer support.

The NET Patient Foundation offer a nurse-run helpline for all patients in the UK and the Ann Edgar Trust provide a regular update which

includes newsletters and details of events and meetings. Both include information about NETs and patient stories on their websites. Ensuring that healthcare professionals are aware of these resources and signpost them for patients is one tangible, low-investment method of helping to support this group of patients.

Additionally, Irene suggests that online forums or virtual groups may be of value. While these are not always easy to set up or run, bringing people together online to share experiences could help relieve the loneliness some patients experience. A 'social' network that puts patients in touch not only with each other, but also with experts from charities, or professional groups, could offer a resource that all NET patients could be referred to for pastoral care, regardless of location. As a starting point, the NET Patient Foundation operates an online forum and closed Facebook page, which is available for Scottish patients.

Accurate information

Clear and accurate information is especially important at the point of diagnosis which, in some cases, will have been after a long wait or previous misdiagnosis. The NET Patient Foundation 'NET Handbook' has been specifically developed to support patients at diagnosis and throughout their pathway and it's clear from patients that this is a resource they appreciate.

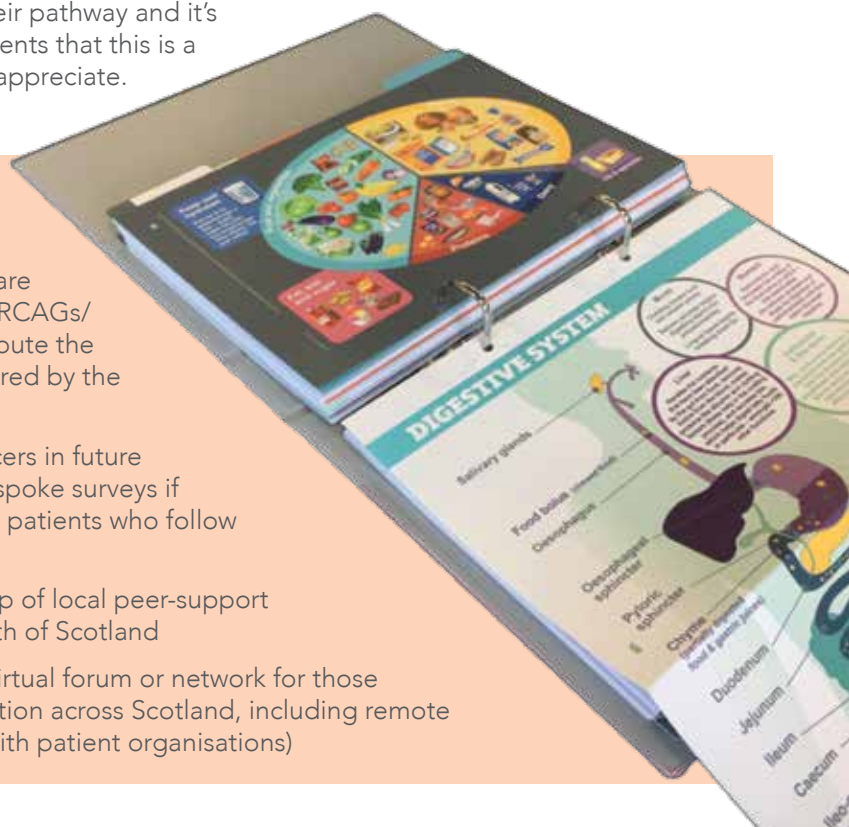
As well as the information she has received from the Beatson, Glynis has found the NET Handbook to be of huge value and she has read this cover-to-cover. She even lent it to the nurse who performs her regular octreotide injections as she wanted to find out more about NETs and NET treatments.

This ready-made resource will be supplied to hospitals and distributed to new NET patients. Ensuring that this happens will be a key way to provide every NET patient with an easy-to-use guide they can keep referring to.

While the observations within this report are based on conversations with individual patients and clinicians in Scotland, the only way to understand the current needs of this patient group with certainty is to ask a significant representational sample for their views. Listening to cancer patients is vital, a fact acknowledged by the existence of the Scottish Patient Experience Survey. However, to date, this information has not been collated or considered for NET patients. Patient-centred care starts with a genuine understanding of the patient. If all patients with cancer are to receive equal levels of care and support, then those who follow a less common pathway also need to be included.

Recommended Actions:

- Encourage adequate signposting of already existing information and patient groups by healthcare professional education, for example, support from RCAGs/ Cancer Networks in encouraging hospitals to distribute the NET Handbook and advise patients of support offered by the NET Patient Foundation and Ann Edgar Trust
- Include NETs and other rare and less common cancers in future Scottish patient experience surveys (or develop bespoke surveys if required) to adequately capture the needs of those patients who follow a less common pathway
- Identify regions that may benefit from the setting up of local peer-support groups such as NET Natter, for example in the North of Scotland
- Consider the development of a dedicated online/virtual forum or network for those affected by NETs to share experiences and information across Scotland, including remote and rural areas (to be developed in collaboration with patient organisations)



Net Patient Foundation Ambition #2:

Cementing the Professional NETwork

Further embed the multidisciplinary approach in the management of NET patients throughout Scotland – with the routine establishment of a multidisciplinary team for all NET cases and the promotion of accurate referrals at all relevant points in the system

The establishment of SCONET and the development of the *Consensus Guidelines for the Management of Neuroendocrine Tumours* marked an important step change in Scotland and the two primary recommendations remain just as relevant two years on:³

- All patients with NETs should be discussed by a specialist NET MDT to agree definitive management
- NET MDTs should include representation from the following specialties: endocrinology, oncology, pathology, radiology, surgery, gastroenterology, nuclear medicine and clinical nurse specialists



Professor Nick Reed consultant in Clinical Oncology at the Beatson West of Scotland Cancer Centre says:

"Speaking as a clinician, there are varying levels of service around the country. Glasgow and Edinburgh have a greater level of facilities as they see the lion's share of patients. Patients from other, smaller areas may have less access to facilities as it's harder to develop a comprehensive service where there are fewer patients. Some areas provide very well in terms of care and expertise, but are unlikely to be able to offer specialist techniques such as gallium 68 PET imaging or Peptide Receptor Radionuclide Therapy (PRRT).

When I started working in Scotland, NETs were not recognised by the other cancer networks, even though all other tumour types were. NETs can be difficult to manage due to the huge range of specialists involved, this is part of the issue.

Rare and uncommon diseases need specialised management, which is why SCONET was created to bring smaller centres on board and make managers in all of the cancer networks aware of issues of NET management in Scotland."

Recognising progress

Significant improvements in access to treatment have been realised in Scotland in recent years. Thanks to greater scrutiny into the healthcare system, it was revealed that certain drugs and facilities that were available in England were not available in Scotland. The Scottish Medicines Consortium's (SMC's) revised approach to orphan drugs, and the success of the NET Patient Foundation and Pancreatic Cancer

UK's joint patient submission to the SMC in 2012, which led to the approval of everolimus, were both significant advances for patients with NETs.

The Beatson West of Scotland Cancer Centre continues to expand its offering for patients with NETs. Earlier this year the Centre was involved in a large-scale NETTER trial for PRRT, a form of radio targeted therapy for the systemic treatment of metastasised NETs. This means the centre now has the

necessary expertise to deliver this therapy to Scottish NET patients, thus saving them from having to travel to one of the ENETs centres in England.

Dr Lucy Wall, an Oncologist at the Edinburgh Cancer Centre says it is an important step forward. *"In my experience, funding requests for PRRT provision are generally approved, but the issue has been that the treatment itself has to take place in London.*

This can present difficulties as some patients aren't physically well enough to travel, and some, who aren't used to travelling, also find the journey and uncertainties about treatment extremely stressful. PRRT being available in Glasgow is a significant advance, the therapy is non-toxic and patients like it."

A man whose wife underwent PRRT in Glasgow shares his thoughts: "It was arranged that my wife would receive treatment in London but it became clear that her general health would make travelling difficult. Her clinical team worked hard to find a solution and eventually it was agreed that she could have PRRT at the Beatson. Not having to travel made a big difference and its probable that this treatment would not have been possible had it not been transferred to the Beatson."

While Professor Reed is proud of the progress that's been made, he highlights the challenge of maintaining this momentum in what is still a relatively poorly understood rare disease area:

"Although the situation in terms of treatment is now more positive, it has taken a long time to get here and you could say that NETs have been 'playing catch-up' compared to other types of cancer.

There have been delays and these have been due to the lack of awareness and understanding by senior management on issues relating to NETs due to their rarity. They simply were not on the radar, not included in other cancer networks and, therefore, not recognised.

It's essential that we continue to move in the right direction and ensure we continue to adequately train our professionals and resource our centres."

Identifying gaps

While the West of Scotland is leading the charge in terms of specialist NET care, good practice can also be found in other regions. However, there are still areas that need improvement.

Dr Paul Newey, Senior Lecturer and Honorary Consultant Endocrinologist, Ninewells Hospital and Medical School, comments on the situation for patients with NETs in Dundee:

"Referrals may end up going to many different specialties. Typically, there is no clear referral pathway as such, as often the diagnosis of a NET hasn't been considered at the point of referral, and is only made following diagnostic imaging, or after a biopsy has been performed. Although patients generally end up being well cared for, there could be an improvement in the coordination between different specialties."

Dundee is a relatively small teaching hospital and there are not enough NET patients to warrant the establishment of a comprehensive NET multidisciplinary service. In regions where this is the case, depending on the individual diagnosis, patients may end up in a variety of clinics and this is often determined by the tumour site, rather than pathology.

Dr Wall from Edinburgh believes this is something that needs to change: "The main issue is that oncology is often quite site focused in terms of care, but there are one or two tumour types such as melanoma, lymphoma, and NETs fall into this category, where we need to be more pathology focused."

While many patients are lucky enough to come under the care of a clinician who has an interest in their specific type of tumour and therefore receive appropriate treatment, they may not get the holistic care that would be provided by a specialist NET team.

Dr Wall says: "Follow-up post-surgery needs to be evidence-based and should follow best practice guidelines – a specialist NET MDT can enable this. Relapse needs to be picked up early so that the treatment options are as broad as they can be. In the case of NET patients, they might not be symptomatic so relapse is more difficult to identify, this is also where a specialist MDT can make a difference."

The absence of a NET-specific MDT in many regions means patients can end up in a surgical setting for a number of years, thus missing out on the care and support that a specialist team could offer.

With the right knowledge and processes in place, inter-hospital referrals in Scotland could work smoothly, as it is generally easier to refer between hospitals in Scotland than in England. Dr Newey says: "Currently, patients with NETs in Dundee will get discussed in an organ-specific MDT (e.g. lung, hepatobiliary), which may not have representation of all the specialties relevant to NETs. However, patients are referred easily between teams and we are fortunate to have access to a wide range of imaging facilities".

Regarding, the use of the ENET and SCONET guidelines Dr Newey believes that these are relatively well-used by the clinicians who are aware of them, or have a particular interest in NETs, but if patients are not in the right setting or with the right specialist then their clinician may not be aware that such guidelines even exist.

Dr Newey continues: "There has been talk of sharing NET MDTs between regions and with larger centres. This could potentially work well for smaller centres like Dundee to be able to link in with specialist MDTs, for example sharing with Aberdeen, Inverness, Edinburgh or Glasgow."

Dr Alex Graveling, a Consultant Physician in Endocrinology from Aberdeen, is similarly keen to share expertise: "There is no dedicated NET clinic in Aberdeen. This would be beneficial. We have MDT meetings currently to discuss cases but a dedicated clinic would allow us to target questions to the appropriate people rather than by emails, letters, etc. It would also be great if the four main Scottish centres could have some form of joint working."

The following patient experienced the downsides of not having access to a specialist NET MDT.

The first NET symptom that the patient experienced was a cough and this led him to visit his GP. He had scans but was not told that anything was the matter. Eventually, as his symptoms continued, he was referred to Crosshouse Hospital. He was sent for biopsies in Glasgow but had to wait for 3-4 months to get the results. During this time the patient and his wife were given very little information and did not know what to expect.

He was told he had cancer and was referred on to the Golden Jubilee Hospital in Glasgow. At the Jubilee, he was anaesthetised and ready to go into theatre when the surgeon discovered that he hadn't had a PET scan and was forced to send him

home. Once the necessary PET scan had been taken he was sent back into hospital for surgery. Because of where the tumour was located at the top of the lungs it was very difficult to access. His ribs were broken and biopsies taken and sent off while he was on the table. The results were found to be benign and he was referred back to Crosshouse.

As previously, there was very little information around what would happen next and he was sent for scans at Crosshouse every six months. Two years later a tumour was found again and he was referred back to the Jubilee where he had further investigations. There was a tumour in the lungs and this time it was malignant. He underwent surgery, with the surgeon removing as much as he could. He was sent home and referred back to Crosshouse.

Again, there was no access to support or a nurse. However, the nurse at the Jubilee recommended that he be seen by Professor Reed at the Beatson, where he now goes for scans and blood tests every six months and where he has access to a specialist nurse.

Both the patient and his wife feel there was a real lack of clarity throughout the process and no sense of who they should call on if his condition was to worsen. They have had to go via their GP whenever they have had a question or needed help, which has then involved a long process of referral. Now that he is being seen at the Beatson they are able to contact the specialist nurse there if needed, but still don't have any support from a Macmillan nurse, or similar, more locally.

Improving the NETwork

Professor Reed says improving the referral pathway is key for NET patients: *"It is important to make correct referrals where possible and ensure that those likely to see NET patients have a good understanding of their specific needs. A patient with a bronchial tumour may be seen by a CNS in a lung cancer clinic who knows nothing about NET bronchial and won't know what needs to be done. They won't necessarily understand that it's not like a lung cancer and will require specific treatment and management."*

"Upper and lower GI surgeons and CNSs, need to know that NET patients need to be followed-up by specialists and treated specifically. It's a glaring weakness in the system and

understandable because they don't realise the differences between tumour types but patients could miss out appropriate management, treatment or participation in clinical trials – potentially reducing their options."

Increasing education and awareness amongst healthcare professionals who are likely to encounter someone with a NET is key.

Irene Wotherspoon, NET CNS at the Beatson, agrees *"Patients with NETs are often admitted through acute medical and acute surgical receiving healthcare professionals and are treated as if they have acute lung, bowel or breast cancer (for example), even though NETs are very different."*

"There is a need to educate these staff and medical/surgical staff in general,

including acute oncology service nurses, so they are able to recognise the symptoms of a malignant NET and have a greater understanding of the specific needs of these patients and who they need to see."

Irene recently carried out a teaching session at the Queen Elizabeth Hospital in Glasgow with palliative care nurses (acute and community), advanced nurse practitioners in oncology and specialist endocrinology nurses – with the aim of increasing recognition of NETs and promoting a better understanding of symptom management. She has also delivered training to GPs via the Gold Standards Framework – where practices meet once a month to discuss patients on the palliative care register.

Recommended Actions:

- Identify a mechanism for sharing learning across and between centres. Look for opportunities to share the expertise (and where possible, facilities) of larger centres with smaller centres, where patient numbers are also smaller
- Ensure all relevant healthcare professionals are aware of and motivated to use the SCONET guidelines
- Improve training for key groups, in particular, specialist nurses or other professionals who may encounter NET patients at any point along the pathway. Identify existing networks where education could be delivered (e.g. Gold Standard Framework meetings in primary care) and consider funding for NET specialist nurses/consultants/patient groups to deliver training
- Encourage the establishment and maintenance of an ENET centre of excellence in Scotland
- In the long-term, consider investment in at least one key NET specialist centre per region, equipped with the capabilities to deliver gold-standard treatment and care, to expand the benefits seen in the West of Scotland and limit travel time for patients for whom this is a challenge

NET Patient Foundation Ambition #3:

Widening the NET

For every Scottish NET cancer patient to be given access to a dedicated specialist NET nurse or equivalent support regardless of location

The national cancer strategy for Scotland aspires to 'support access of equity to specialist care regardless of geography'. CNSs play an important role in the pathway of any cancer patient, providing a source of ongoing support and expertise. However, for patients with a NET in Scotland, access to a dedicated CNS is not a given. There are currently a limited number of dedicated NET nurse specialists, although some patients will be able to see another CNS (e.g. endocrine or upper GI) with some knowledge of NETs.

Thankfully, in 2016 a new NET specialist nurse post was created at the Beatson when it was recognised that a CNS was available for every other cancer type. Since taking on the role, Irene Wotherspoon has been able to offer a range of services which would not have been available to NET patients otherwise, some examples of which are included below:

- Referrals to relevant support services (around 17% of patients) including: district nurses, Macmillan Nurses, hospice in-patient beds, hospice outpatient symptom management clinics, Maggie's Centre, social work for benefits, Marie Curie Nursing Service, psychological services (including spouses)
- Home visits where needed
- Nurse-led clinics to administer somatostatin analogues
- Management of symptoms such as diarrhoea, pain and nausea, providing a 'one-stop shop' for information and advice
- Psychological support – expert information, the ability to explain side effects and treatments, advice on how to manage symptoms, advice on when to call helpline

In order to accurately assess the impact she has had, Irene has also surveyed her patients with the support of the West of Scotland Cancer Network (WoSCAN). The results of this research were included in a poster, 'Evaluating the Impact of the Specialist Nurse', excerpts of which are included below:

The attendees* were asked to rate using a Likert scale ranging from 1 to 5. (1 – extremely poorly, 5 – extremely well).
86–94% of questions were answered 'well' or 'extremely well'

*40 questionnaires were distributed through outpatient clinic, 50% response rate

How well has your CNS...?	1	2	3	4	5
Helped you to understand your diagnosis			5	14	76
Given information about your condition			5	21	74
Managed your symptoms			11	17	72
Been a contact point with the rest of the team			6	11	83
Supported other members of the family/friends			6	19	75

Qualitative insights were also gathered as part of the research with patients stating the following aspects of support as being most important to them:

- Having the personal contact
- Explaining processes involved in my treatment
- Just having someone to talk to
- Having someone who both understands my condition and empathises with the nature of my illness
- Ability to understand my specific requirements and meet my needs based on this

Additionally, one patient commented:

"I have only met Irene once, but having been diagnosed 15 years ago it is a bit late for some help. She told me about the help group which was useful. In 15 years, I have never met anyone with a NET. I would like to think that if my condition worsens/becomes terminal she will be well placed to help me and my family. I wish she had been there 15 years ago when I was very ill with two teenage children."

As the research suggests, having the support of a specialist nurse clearly makes a difference for NET patients. However, while Irene's post will cover many (she is responsible for the West of Scotland, a sizeable chunk of the population), there will still be areas that are not well-served and, in some instances, patients simply won't get to see a specialist nurse of any description. Irene shares her perspective:

"They might see an outpatient nurse to administer injections and they might see a chemotherapy nurse if this is part of their treatment (only suitable for patients with high-grade NETs) but they won't have the time, training or expertise to provide them with the psychological support and specialist info they need. Even when they get to see a nurse with some level of specialist knowledge, they are likely to be balancing this with another role."

Dr Lucy Wall, a Consultant Medical Oncologist from the Edinburgh Cancer Centre at the Western General Hospital mirrors Irene's views, stating that they would like a dedicated NET nurse in the Centre, and are currently recruiting:

"Most hospitals don't have one that is dedicated to NETs. Usually it is added to other specialities, which is understandable but not the same as a dedicated nurse. At the time of diagnosis in particular, people are very upset and are desperate for information. This is where a NET specialist nurse would be great. Also, to support community nurses with NET care, at the moment my secretary ends up doing this."

Dr Alex Graveling from Aberdeen, paints a similar picture: *"We have a CNS who covers NETs but she wears a lot of hats. She only really sees the ones who see the oncologists, not all of them. The endocrine nurses have traditionally done a lot with NET patients, they do the practical aspects (e.g. injections) as well as the psychological support. There is support there but it would be nice if the service was more joined up for NET patients."*

When a specialist nurse is not in place the pathway for patients can be a lonely one, with limited access to information.

One patient with a lung NET and his wife feel that what would really improve outcomes for NET patients, is to be able to see a specialist nurse who understands their particular kind of NET on a monthly or at least three-monthly basis. Someone to 'come and see how you are doing and how you are getting on'.

Because he is not on any treatment, he hasn't had the regular contact that some other patients might and both he and his wife have felt the lack of that.

Given the benefits that have been seen in Glasgow, there is a strong case for widening access to specialist NET nurses, particularly as this aligns with the goals of the national cancer strategy and is a key recommendation of the SCONET guidelines. In some cases this may mean the creation of new posts and in others sharing access to nurses in larger centres. Although this may require upfront investment, this is counterbalanced by the considerable cost savings to be made in terms of accurate referrals, effective management of symptoms and a reduced time-burden for consultants.

Recommended Actions:

- Scottish audit to ascertain current access to NET specialist nurses and identify key regional gaps
- Funding of specialist NET nurse posts in key locations (to ensure adequate coverage outside of the West of Scotland)
- Set up a professional (online) network for nurses specialising in NETs (even when this is split with other specialisms) to enable sharing of knowledge and learning
- Additional NET training/information for nurses working in key roles likely to encounter NET patients, e.g. outpatient nurses, chemotherapy nurses, oncology nurses

SUMMARY

A great deal of progress has been made in Scotland and this report is littered with examples of good practice. However, to maintain momentum and avoid slipping backwards, it is essential that NETs remain front of mind when it comes to decisions about the provision of care. The aim must be for all NET patients in Scotland to have access to a similar standard, regardless of circumstance and geography. The ambitions outlined previously offer practical and realistic aspirations for NHS Scotland when considering future policy.

- Ensure access to ongoing information, support and peer-to-peer communication for all those affected by malignant NETs in Scotland
- Further embed the multidisciplinary approach in the management of NET patients throughout Scotland
- For every Scottish NET cancer patient to be given access to a dedicated specialist NET nurse or equivalent support regardless of location

The motivations behind these ambitions are perhaps best summed up by the husband of one Scottish patient: "NET patients are not looking for special treatment, they just want to be treated the same as any other cancer patient. For a lot of people with NETs, their experience is not what it should have been, that's changing and we need to make sure it continues to do so."

"We welcome the considerations outlined in this report which highlight some important recommendations for improving the NET patient experience throughout Scotland. The Ann Edgar Trust is working in partnership with the Net Patient Foundation to ensure greater access to information and support through peer-to-peer (NET Natter) groups and working with healthcare professionals to raise awareness of NETs. Our social media, Newsletters and attendance at NET clinics and other professional fora are helping to make a difference to the lives of Scotland's NET patients and their families. We look forward to hearing about how the recommendations in this report are being taken forward." The Ann Edgar Trust



References

1. NET Patient Foundation. Chapter 10 Report: One-size fits no-one. 2016.
2. Scottish Government. Beating Cancer: Ambition and Action. 2016. Available from: <http://www.gov.scot/Publications/2016/03/9784>. Accessed 16 October 2017.
3. SCONET. Consensus Guidelines for the Management of Patients with Neuroendocrine Tumours. 2015. Available from: <http://www.woscan.scot.nhs.uk/wp-content/uploads/FINAL-PUBLISHED-SCONET-Guideline-v1.1-July-2015.pdf>. Accessed 16 October 2017.
4. ISD Scotland – Scottish Cancer Registry. October 2017.
5. National Institute for Health and Care Excellence. Suspected cancer: recognition and referral. NICE guideline [NG12]. 2015. Available at: <https://www.nice.org.uk/guidance/ng12>. Accessed 16 October 2017.