

POLICY RECOMMENDATIONS

on Neuroendocrine Tumours (NETs)



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Foreword

While the European Union has shown its commitment to supporting the fight on rare diseases, numerous challenges in the management of rare cancers such as Neuroendocrine tumours (NETs) remain. Low awareness, rise in incidence, difficult early diagnosis, inequalities in access to care and treatment across Europe and the need for support to research and innovation are all aspects on which further efforts are needed to improve the current situation.

As Members of the European Parliament, we strive to create policies that aim to improve the management of care for patients a reality. Only through appropriate implementation of legislation such as EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare can we improve the management of conditions like Neuroendocrine Tumours. The successful setting up of European Reference Networks (ERN) is one of the examples through which this can be achieved.

These policy recommendations outline the challenges of NETs and their impact on patient lives. They are intended to provide guidance to protect and improve human health through better management of these conditions and contribute to EU and Member States' policy-making in the field while underlining the need for mobilization of all the Neuroendocrine community. With thanks to the Experts from EU Member States contributing to this paper, the recommendations are based upon experience of living with and managing care for NETs.

We are pleased to support them and remain committed to strive for better management of NETs in the European Union.

Françoise Grossetête MEP



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Glossary

CANCON – Initiative launched by the European Commission and supported by Member States that aims to raise cancer survival and reduce cancer mortality by creating a European Guide on Quality Improvement in Comprehensive Cancer Control.¹

Council of the European Union – The Council of the EU represents the Member States' governments. Also known informally as the EU Council, it is where national ministers from each EU country meet to adopt laws and coordinate policies.²

European References Networks (ERNs) – EU legislation requires the European Commission to support Member States in the development of European Reference Networks (ERN) to link existing centres of excellence in rare diseases and/or recognise existing networks of centres. Their objective will be to encourage better access of patients to highly specialised and high quality and safe care, European co-operation on highly specialised healthcare, pooling knowledge, improving diagnosis and care in medical domains where expertise is rare, helping Member States with insufficient number of patients to provide highly specialised care, maximising the speed and scale of diffusion of innovations in medical science and health technologies and being focal points for medical training and research, information dissemination and evaluation.³

Horizon 2020 – Horizon 2020 is the biggest EU Research and Innovation programme ever with nearly €80 billion of funding available over 7 years (2014 to 2020) – in addition to the private investment that this money will attract.⁴

Innovative Medicines Initiative (IMI) – The Innovative Medicines Initiative (IMI) is a partnership between the European Union (represented by the European Commission) and the European pharmaceutical industry (represented by EFPIA, the European Federation of Pharmaceutical Industries and Associations). It is the world's biggest public-private partnership (PPP) in the life sciences and works to improve health by speeding up the development of, and patient access to, innovative medicines, particularly in areas where there is an unmet medical or social need. It does this by facilitating collaboration between the key players involved in healthcare research, including universities, the pharmaceutical and other industries, small and medium-sized enterprises (SMEs), patient organisations, and medicines regulators.⁵

Joint Actions – Joint Actions are initiatives that have a clear EU added value and are co-financed either by competent authorities that are responsible for health in the Member States or in the third countries participating in the European Commission Health Programme, or by public sector bodies and non-governmental bodies mandated by those competent authorities.⁶

Orphanet – Orphanet is the reference portal for information on rare diseases and orphan drugs, for all audiences. Orphanet's aim is to help improve the diagnosis, care and treatment of patients with rare diseases.

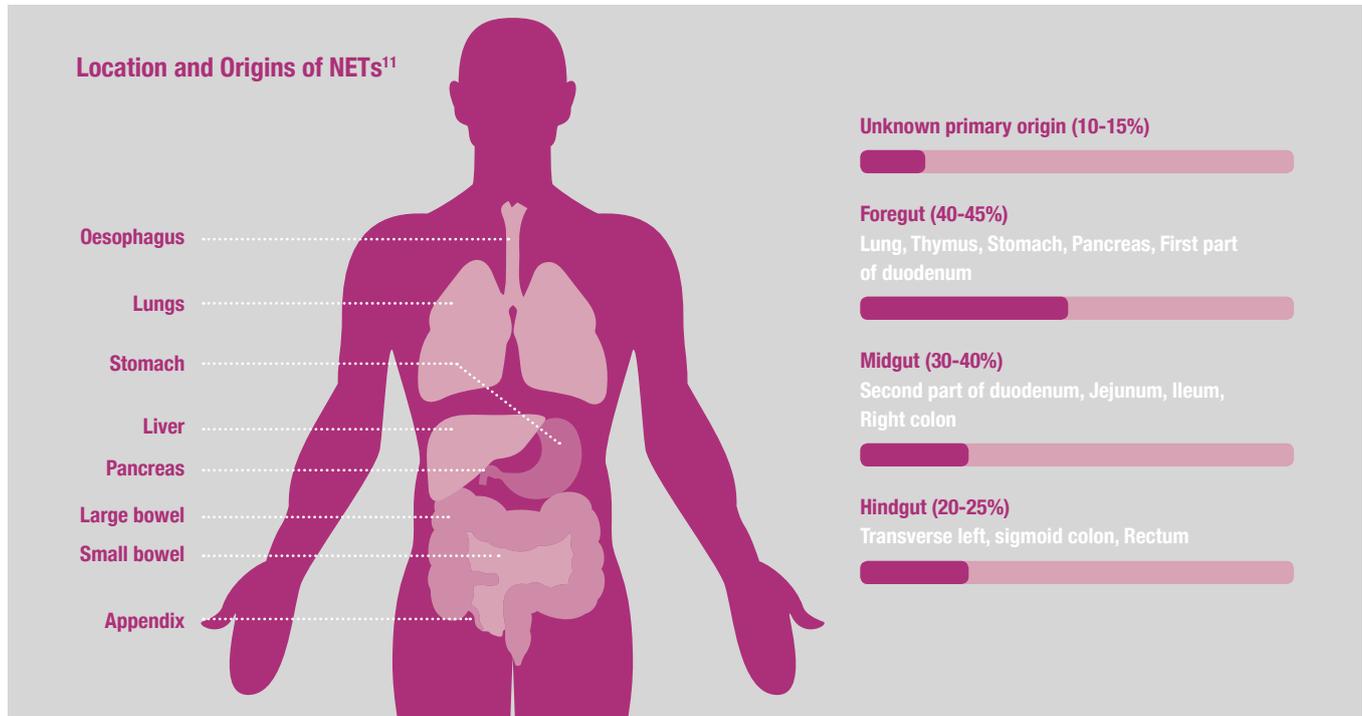
Orphan Medicinal Products Regulation (OMP) – The EU Regulation 141/2000 on Orphan Medicinal Products is a legislation that was introduced by the EU to stimulate the research and development of orphan drugs by providing incentives for the development of orphan and other medicinal products for rare disorders.⁷

Patients' Rights in Cross-Border Healthcare Directive (CBHD) – The EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare creates a legal framework for the patient's right to seek healthcare in another Member State and to benefit from cross-border healthcare services.⁸

RareCareNet – RareCareNet aims at building an information network to provide comprehensive information on rare cancers to the community at large (oncologists, general practitioners, researchers, health authorities, patients and their families).⁹

II. What are NETs?

Neuroendocrine Tumours (NETs) are a family of cancers that cause tumours in the neuroendocrine system. The neuroendocrine system consists of nerve and gland cells. It produces hormones and releases them into the bloodstream. NETs are generated by cells that release the hormones. The majority of NETs are found in the intestine, pancreas and the lungs.¹⁰



Tumours have behaviours ranging from relatively benign to highly malignant¹² and can be fatal especially if left untreated. In addition to the types of NETs highlighted above, multiple endocrine neoplasia, pheochromocytomas, paragangliomas and medullary thyroid cancers each represent unique medical challenges. NETs are not limited to the gut and lungs but also involve other organs (adrenal glands, thyroid, autonomous nervous system, etc). European expert networks focused on these tumors have emerged during the last decade such as ENSAT and ERCUSYN. The networks perform clinical research, establish registries and have allowed significant improvement in our knowledge for the treatment of patients. In these various multidisciplinary relevant networks for NETs, the endocrinologist plays a leading and coordinating role. The perspective of integrating the current endocrine-related networks in a common approach could support even better co-ordination.

NETs and their symptoms severely impair quality of life. Diagnosis is often difficult as symptoms resemble those of other more common diseases. For this reason, and because NETs are relatively rare¹³, patients are commonly misdiagnosed and diagnosed fortuitously. The time taken to diagnose impacts the treatment options for the patient. Researchers are rapidly developing new screening and imaging technologies which could prove crucial in improving diagnosis.

NETs can be treated through:

- Surgical therapy (cure, debulking treatment/ prevention of complications).
- Symptomatic therapy (control of hormonal symptoms related to carcinoid syndrome).
- Antiproliferative/ anti-tumour therapy (control tumour growth).¹⁴

Being given a diagnosis of having a potentially lethal cancer, such as NETs, has life changing effects for the patient and also for their families. Progress of the diseases can be slow, but it can also be lightning fast.

Factbox

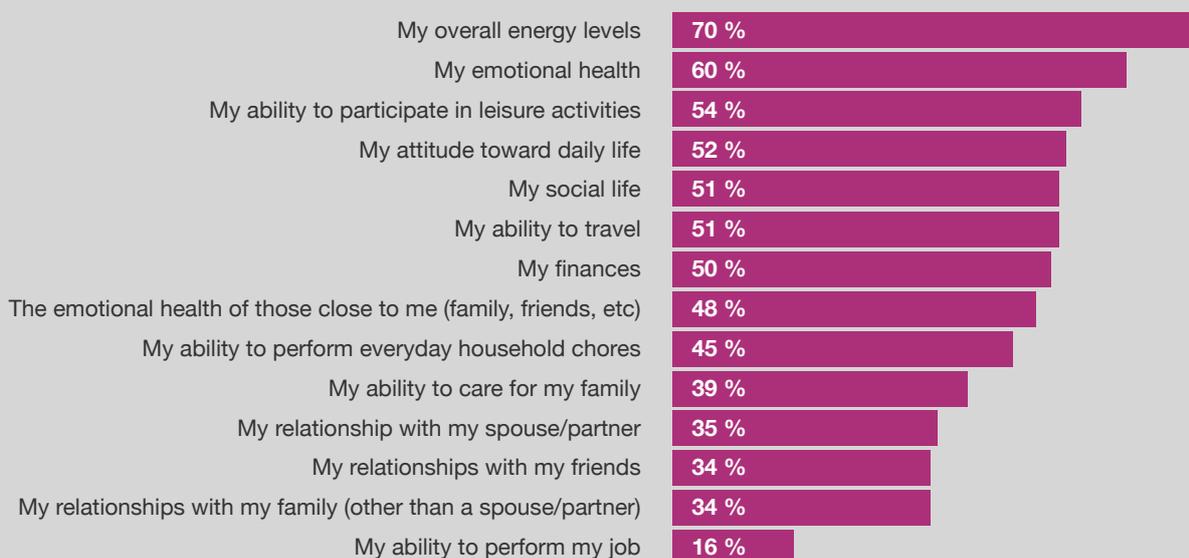
- Five out of every hundred thousand people are diagnosed with NETs each year¹⁵
- NETs are difficult to diagnose. For example, diagnosis of tumours in the stomach, intestine and pancreas (GEP-NET) can be delayed up to 10 years¹⁶
- Because NETs are slow-growing tumours, patients may survive for many months after diagnosis.¹⁷
- 60-80% of patients are diagnosed at an advanced stage, often because of similarity of symptoms to other conditions. Therefore, although NET incidence is relatively low, prevalence is quite high¹⁸
- Important research into the heritability of NETs is ongoing and may have important conclusions in terms of diagnosis potential
- Some NETs are inherited disease driven by genes that spread the disease in families of affected members. Therefore screening for genetic causes and early recognition of the disease in gene carriers is an important aspect.
- Within the family of NETs, some conditions are especially rare such as rare pancreatic tumours
- Some NETs also oversecrete hormones in the circulation that are responsible for significant morbidity and mortality

The Zebra, and NET Cancer Day

The NET Cancer Day is organised by the International Neuroendocrine Cancer Alliance¹⁹ on 10 November each year to raise awareness about this condition

The colours of the Zebra are used to represent NETs to highlight the challenge of diagnosis – when one hears hooves, consider that it may be the rarer zebra and not necessarily the more common horse!

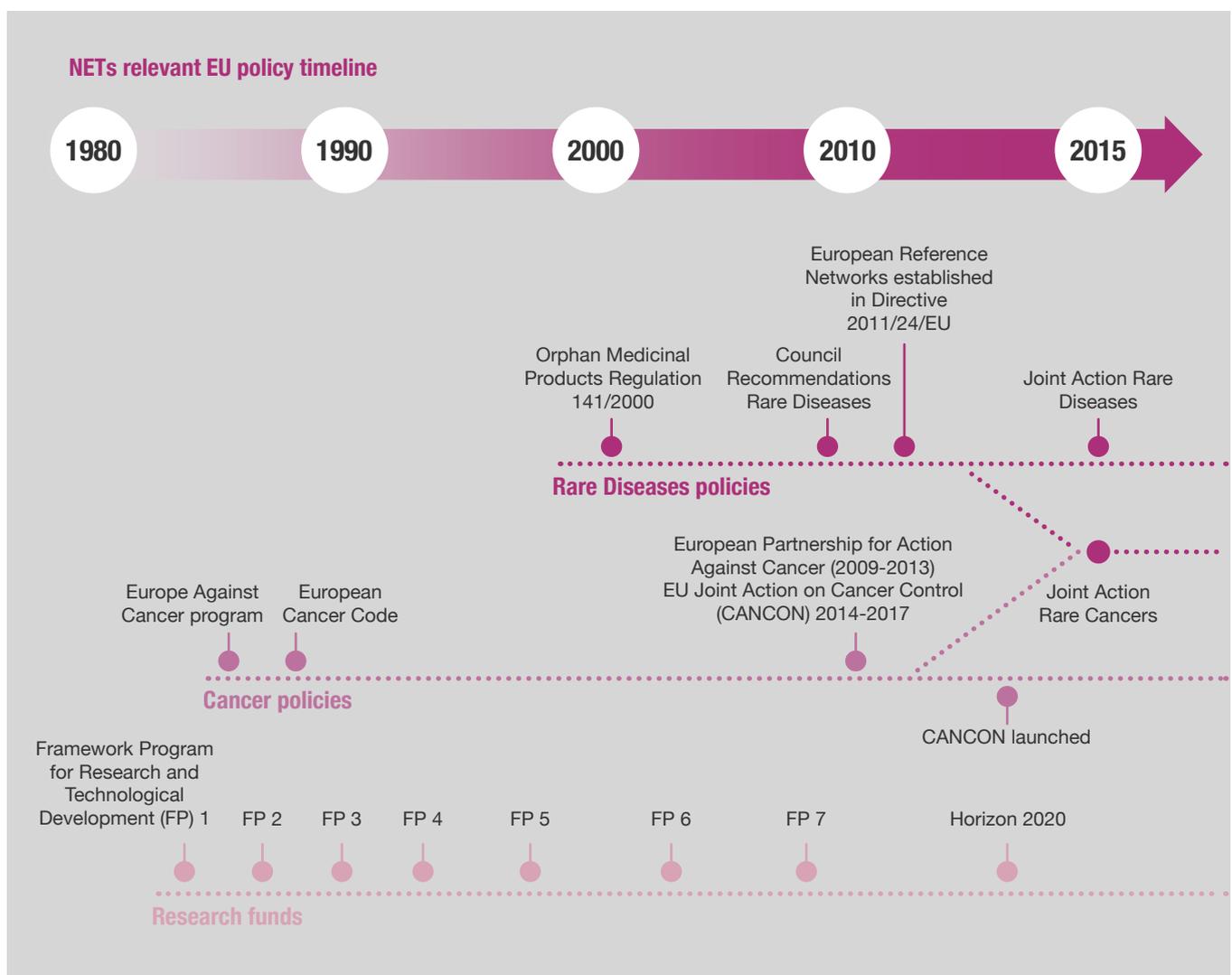
Negative impact of NETs on different aspects of life²⁰



III. Adapted EU Policies for NETs?

The European Union has in the last thirty years launched a number of policies and legislations to try and improve public health provisions. Examples of successful developments include the Patients' Rights in Cross Border Healthcare Directive²¹, the Orphan Medicinal Products Regulation²² and the development of an effective single system of approval of medicines for the European Union. The aim of these legislations, is to speed up patients' access to the treatment, care and expertise they need and to seek to provide a more equitable access for EU citizens to such medicines and specialist medical expertise.

The European Union has also shown the added value it can bring to the coordination and support of national efforts on cancer and rare diseases through the adoption of recommendations in these fields and follow-up establishment of national specific plans for these conditions. NETs find themselves at the confluent of these policies by being recognized as a family of rare cancers²³. Rare cancers policy should clearly be a focus for the NETs community.



These policies have led to the development of different care pathways in Member States in Europe and the development of best practices in the management of NETs.

EXAMPLE OF FRANCE AND THE RENATEN²⁴

Since 2009 following a call of the French health authorities and National Institute for Cancer several networks for rare diseases have been set up in France. The RENATEN Network is dedicated to patients with any kind of NET. This network was developed by members of a French medical scientific society, the Groupe de recherche des Tumeurs Endocrines (GTE), a multidisciplinary group.

The RENATEN network involves 16 centers spread throughout the French territory under the supervision of a coordinating center. Each center corresponds to a multidisciplinary team based in a university hospital (CHU). These teams have developed:

1. Patient care at the regional level with multidisciplinary expert staff. For example, the case of 3745 patients with NETs were examined by the RENATEN network during 2013;
2. Patient care at the national level with one monthly web-staff during which physicians of each center discuss very specific and rare cases;
3. Organization of a national oncogenetic network in France to provide free genetic analysis searching for alterations of genes leading to NETs in affected patients;
4. Registry of NETs in France;
5. Good practice recommendations and expert consensus for care;
6. Teaching to non expert physicians with at least one meeting per year in each region of France and one national congress;
7. Clinical research. More than 40 clinical trials have been conducted and more than 23 scientific papers have been published in peer-reviewed journals since 2009;
8. Information for patients, their families and interactions with patient's association. The close interaction between RENATEN and patients is illustrated by several RENATEN research grants funded by patient's association.
9. The RENATEN Network was evaluated in 2014 by the French health authorities and National institute for cancer and reappointed for 5 years.

THE SITUATION OF NET PATIENT CARE IN SPAIN²⁵

1. The Spanish National Health System (Sistema Nacional de Salud, SNS) is the collection of public health services. Management of these services has been progressively transferred to the 17 autonomous communities of Spain. The activity of these services is harmonized by the Interterritorial Council of the National Health System (Consejo Interterritorial del Servicio Nacional de Salud de España, CISNS) in order to give cohesion to the system and to guarantee the rights of citizens throughout Spain.
2. As a consequence of the decentralization, the mobility of patients between communities has been severely impaired in Spain, mainly due to budget constrictions and limitations to budget mobility between communities. Except for very few specific interventions that are organized at a national level (i.e. organ transplantation), even within a given autonomous community, diagnosis and treatment of rare diseases such as NETs are not centralized in recognized specialized centres, but are rather managed wherever they happen to occur. Thus, mobility of a NET patient to a NET specialist is dependent upon the will and knowledge of Doctor and patient.
3. Despite all of these barriers there are certain centers that are able to develop high standards of care for patients with NETs and treat a significant number of NETs patients. However, the health system organisation does not permit the development of centers managing the care of higher

volumes of patients with rare diseases. This is the reason why no single centre in Spain has ever applied to the ENETS Centre of Excellence Network, despite the active involvement in the field of many Spanish NET specialists, as one of the requirements for this includes to manage at least 80 new patients with NET per year.

4. In this context, a Spanish network for NETs - GETNE (Spanish Task Force for Neuroendocrine Tumors) was developed in 2004. GETNE is a scientific society composed by specialists from multiple disciplines that involves 57 academic and community sites representing all regions of Spain. The main initiatives of GETNE in the field are:
 - RGETNE: this is the National Cancer Registry for Gastroenteropancreatic Neuroendocrine Tumors coordinated by GETNE, that currently has about 2500 patients registered. This Registry provides valuable insights that may contribute to understand regional disparities in the incidence, patterns of care and survival.
 - NET Discovery: more recently, GETNE has also launched a NET sample collection network (including blood, saliva and tumor samples) linked to the Spanish NET Registry (RGETNE) to promote translational research.
 - Clinical Trials: GETNE is also actively involved in the development of new drugs or treatment strategies, and has a large experience in conducting and coordinating national and international investigator-initiated clinical trials
 - Continued Medical Education: GETNE organizes a yearly international NET Symposium, and several national educational events for non-expert physicians and young specialists in the field. GETNE elaborates clinical guidelines for NET diagnosis and treatment.

ENETS – TACKLING NETS WITH EUROPEAN SPIRIT

The European Neuroendocrine Tumor Society founded in 2004 is the leading international multidisciplinary organization for the care of neuroendocrine tumor patients. It has over 1300 members with a specific interest in tumours including oncologists, surgeons (gastrointestinal, liver, pancreas, endocrine and thoracic), endocrinologists, gastroenterologists, pathologists, nuclear medicine physicians, radiologists, nurses, basic scientists and patient advocates. ENETS has recognized the need to enhance patient care as well as improve the understanding of NETs in the wider medical community. Thus ENETS in addition to its Annual Conferences attended by more than 1500 participants and Summer Schools for young investigators also publishes guidelines for NET management, guidelines for standards of care regarding investigations and therapies, as well as promoting collaborative research and encouraging investigators in their clinical and research development. ENETS has integrated specialist NET nurses within its organization and Advisory Board. The standard of patient care and survival has been enhanced by the development of ENETS Centers of Excellence. There are currently 34 ENETS Centers of Excellence which have each been independently audited and fulfill the following criteria

- EU Centers that meet the standards of care for neuroendocrine cancer as defined by ENETS and the independent audit experts
- Guarantee the patients best quality care
- Provide the patients with choice
- Build a EU network of expertise on neuroendocrine cancer to foster growth, collaboration and generate evidence from patient outcomes and research/clinical trials
- Adherence to standards of care and protocols of management thus enabling more efficient use and cost of therapies and enhancement of patient support and care

The activities undertaken by ENETS demonstrates a clear added value to European co-operation between medical experts, which fits closely with the spirit of European Reference Networks. The Audit specifications and process may be a helpful example of a working “European Reference Network” which could be appropriately adapted for the planned substantive ERN.

IV. Key issues in the management of NETs

1. Knowledge & Diagnosis

NETs are a challenge to diagnose. Depending on where the NET's origin is, symptoms will vary. If symptomatic, misdiagnosis with more well-known conditions such as Irritable Bowel Syndrome (IBS) is also common given that symptoms are similar and many physicians have not been informed about NETs. For example, NETs in your digestive system may cause pain or discomfort in the abdomen that comes and goes²⁶. Some NETs may overproduce a hormone-like substance such as serotonin which will manifest through symptoms called the carcinoid syndrome. There are a variety of syndromes related to NET tumours. However, in most cases symptoms are often non-existent, mild or nonspecific making the diagnosis of NETs a challenge, leading to late diagnosis. In the case of tumours in the stomach, intestine and pancreas (GEP-NET) diagnosis can be delayed by up to 10 years²⁷ and 44%-73% of GEP-NET patients in Europe are diagnosed with metastatic disease²⁸. This is especially concerning given that NETs are incurable once they advance to unresectable metastatic disease.²⁹

It is clear that greater knowledge of medical professionals is needed to diagnose NETs more effectively. Initiatives have taken place at regional and national level led by medical experts on NETs. This is work that is mostly undertaken informally and by persons with a passion for sharing their knowledge with the aim of improving diagnosis and care for NETs patients. It is clear though that resources and support from national governments are needed given that education of primary and secondary care professionals is the objective. This translates into a very large target audience that NETs specialists need help to reach.

The experience of patients in accessing effective diagnosis, and living undiagnosed or misdiagnosed, must be a central focus. Patients report difficulties getting access to the most innovative diagnostic technologies, which is disturbing as it can delay access to appropriate care and appears to be a false economy. The provision of resources by national governments and demonstration of support towards an European Reference Network (ERN) on NETs would be crucial to its success.

Why is detection of NETs difficult?

- Awareness – physicians are often unfamiliar with NETs
- Size - some NET cancers can be less than a centimeter in size
- Location – NETs can occur in a number of places
- Symptoms – can vary enormously depending on NET
- Testing – given differences in NETs, specialized tests are necessary

What are the symptoms of NETs?

- Flushing, acute diarrhea, palpitations, wheezing
- Low sugars, sweaty, faint
- Recurrent stomach ulcers
- Production of hormones

Methods to diagnose NETs

- CT, MRI, ultrasound, molecular imaging, blood test, urine test and endoscopy, octreotide and MIBG scans, gallium PET

The importance of diagnosis

- NETs often have an associated long-term clinical burden, with the stage of discovery highly impacting the 5 year survival rates (from 93% survival rate in well differentiated localised disease, to 14% in well differentiated disease with distant metastases)³¹

Improving diagnosis and knowledge is one of the focus of the European Union action in the field of rare diseases and cancer.

Several valuable resources for patients and healthcare professionals have been developed at European Union level through legislation and funding such as Orphanet, RareCareNet and CANCON to help to raise awareness and provide information to citizens.

CANCON aims to contribute in different ways to reducing the cancer burden in the EU by bringing together leading medical and policy experts on cancer from EU Member States. These key elements will be combined with other relevant aspects of cancer control to create a *European Guide on Quality Improvement in Comprehensive Cancer Control*. One of the major areas of focus of this Guide will be improving cancer screening.³²

Furthermore, Joint Actions on Rare Diseases and Rare Cancers have been launched in the second half of 2015 during the Luxembourg Presidency of the EU Council.

RECOMMENDATIONS

Member States should support the NET community in its effort to educate healthcare professionals and foster knowledge-sharing on NETs regarding symptoms and diagnosis methods.

Member States that do not have a focused policy on NETs should consult specialists and utilise recommendations for best practices drafted by those specialists, based on their experience.

The NET community should work collaboratively on Knowledge & Diagnosis to identify recommendations for the European Union such as on hurdles to access to appropriate diagnosis and awareness raising on NETs.

2. Patient Journey

When a person is diagnosed with a NET, it may be the result of a journey involving unexplained and disturbing symptoms and misdiagnosis²¹. NETs affect people of any age, and can be slow-growing or very aggressive depending upon the type, location and spread of tumours. Time to diagnosis is critical.

That is because the first line of treatment, treatment, curative surgery, is mainly only possible if the tumour has not metastasised over time. Unfortunately a significant proportion of patients are diagnosed only after the tumour has spread.³³

The impact of NETs on the individual, whether diagnosed or not, is high. The symptoms of flushing, palpitations, chronic diarrhea and stomach ulcers disrupt the person's life and health. The psychological effect of cancer on the individual and family is well established. The symptoms of NETs, concerns about healthcare, implications for the patient's plans for the future, and the impact of all of this on the patient's mental health are life changing. The effect of NETs on the lives of family and friends, including as unpaid carers, mean that a diagnosis of NETs does not just affect one person.

Treatments can be utilised to treat the symptoms caused by NETs and slow disease progression. Quality of life factors should be taken into account as a priority, whereby those treatments that reduce symptoms and slow disease progression are seen as beneficial to the patient where curative surgery is not possible.

The availability of expert medical professionals to NET patients is a crucial factor. Treatment usually needs to involve 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.

Specialist NET nurses also play a key role in the provision of a high standard of care. The coordination of different specialist interventions (including booking and allocation of resources), provision of clear information based upon experience of NETs, and the prescription of medicines are within the remit of specialist nurses in several well working care networks. To optimise patient care, all centers of reference should have a specialist NET nurse.

To date the management and structure of care for NETs in Europe has developed itself through:

- The establishment of national networks with the support of the Member State hosting and the national medical expert community,
- The work of ENETS through the designation of centers of excellence and regrouping them into a network aiming to disseminate best practices and state of the art care for NETs.

In 2014, the EU Patients’ Rights in Cross Border Healthcare Directive³⁴ enshrined in its Article 12 the establishment of European Reference Networks (ERNs) for rare conditions and those that require specialist care. An important aspect for European Reference Networks is that they are clearly patient focused, given that the mandate is granted by a Directive focused on improving care for patients. It will be important to ensure that existing national networks are facilitated and leveraged for an additional value at EU and national level, rather than becoming too complex and bureaucratic.

System for accreditation of Centres of Excellence by ENETS

| Certification awarding body |  | Owner of the COE program awarding body |
|------------------------------------|--|--|
| ENETS CoE Certification Commission | <ul style="list-style-type: none"> • ENETS Auditors, specialists • Chaiman of the ENETS CoE Program • One member of ENETS EXECUTIVE COMMITTEE | <ul style="list-style-type: none"> • Further development of the catalogue • recommendations on awarding the CoE certificate |
| Certification body | GSG Consulting Certification | <ul style="list-style-type: none"> • Coordinator and guarantor for an independent certification proceure • Recommendations on awarding the certificate |
| Team of Specialists | ENETS Auditors | <ul style="list-style-type: none"> • Appointed by ENETS and qualified via GSG • Evaluation of the Centres |

RECOMMENDATIONS

A European Reference Network covering NETs, which could significantly improve patient care, as a more formal step for currently existing national networks would be beneficial and it is important that any future European Reference Network take into consideration the views of experts in this field and rely on already existing networks.

Considerable variation exists across Europe in the care pathway for NETs and it is important that best practices from different Member States are identified and disseminated, for example through EU initiatives such as CANCON.

A very effective way to improve treatment is to improve diagnosis of patients before tumours have spread to improve chances of surgery being possible.

Member States should improve access to specialist care effectively including surgeons, physicians and nurses. Standards of care developed by ENETs and national networks or centres of expertise should be utilised to fight inequalities in treatment of NETs in Europe.

Member States should support a multidisciplinary treatment approach for NET patients by including all relevant experts across disciplines to identify appropriate treatment.

Governments and healthcare providers must proactively consult NET patients and medical experts on NETs when elaborating policies affecting NET patients.

The NET community should work collaboratively on patient journey to identify recommendations for the European Union.

3. Research & Innovation

A major incentive for undertaking action on NETs at EU level is the fact that the Union is a leader in innovation and has one of the largest funds available for research. A number of companies and academics based in the European Union have contributed to great steps forward in medical science that have enabled today's possibilities of diagnosis and treatment for NETs patients. The important contribution to economic prosperity of the science and medical sectors is recognised in all European Union Jobs & Growth policies.

Research is being carried out to understand what are the causes of NETs, how do they form, to formulate more effective diagnostic tools as well as discover new treatment options. Like for most rare diseases, the limited number of patients and the scarcity of expertise poses great challenges. Appropriate support is therefore needed to teams of dedicated specialists in Europe so that the management of care of the condition could be improved every day.³⁵

The European Union has several instruments to fund research and address unmet public health needs, including the Horizon 2020 program and the European Public-Private Partnership IMI 2 (Innovative Medicines Initiative). It is essential that these programs and partnerships do not overlook areas like NETs.

In the field of rare diseases EU legislations and initiatives such as the Orphan Medicinal Products Regulation³⁶ have been a driving force in the development of treatment options with over 1000 positive opinions in favour of orphan designations 1000 orphan designations granted by the Committee for Orphan Medicinal Products (COMP) of the European Medicines Agency. At the time the Regulation was designed to support the development of new therapeutic options for rare disease.

“As a medical scientist I have seen first-hand the kind of breakthroughs that can come from rewarding innovation in healthcare. We need to ensure that the R&D focused policies that we have created at EU level, translate into real results on the ground and that the EU remains a place where investors in medical research are rewarded for their results.”

Dr. Kay Swinburne MEP (ECR, UK)

RECOMMENDATIONS

Member States should ensure appropriate incentives are in place to support the development of additional treatment options for NETs.

The NET community should work collaboratively on research & innovation to identify recommendations for the European Union such as on an assessment of opportunities for support to research for NETs under Horizon 2020 and research funding programs.

V. Recommendations Summary & Conclusions

KNOWLEDGE & DIAGNOSIS

Member States should support the NET community in its effort to educate healthcare professionals and foster knowledge-sharing on NETs regarding symptoms and diagnosis methods.

Member States that do not have a focused policy on NETs should consult specialists and utilise recommendations for best practices drafted by those specialists, based on their experience.

The NET community should work collaboratively on knowledge & diagnosis to identify recommendations for the European Union such as on hurdles to access to appropriate diagnosis and awareness raising on NETs.

PATIENT JOURNEY

European Reference Network covering NETs, as a more formal step for currently existing national networks would be beneficial and it is important that any future European Reference Network take into consideration the views of experts in this field and rely on already existing networks.

Considerable variation exists across Europe in the care pathway for NETs and it is important that best practices from different Member States are identified and disseminated, for example through EU initiatives such as CANCON.

A very effective way to improve treatment is to improve diagnosis of patients before tumours have spread to improve chances of surgery being possible.

Member States should improve access to specialist care effectively including surgeons, physicians and nurses. Standards of care developed by ENETs and national networks or centres of expertise should be utilised to fight inequalities in treatment of NETs in Europe.

Member States should support a multidisciplinary treatment approach for NET patients by including all relevant experts across disciplines to identify appropriate treatment.

Governments and healthcare providers must proactively consult NET patients and medical experts on NETs when elaborating policies affecting NET patients.

The NET community should work collaboratively on the topic of patient journey to identify recommendations for the European Union.

RESEARCH & INNOVATION

Member States should ensure appropriate incentives to support the development of additional treatment options.

The NET community should work collaboratively on research & innovation to identify recommendations for the European Union such as on an assessment of opportunities for support to research for NETs under Horizon 2020 and research funding programs.

Nothing about us without us! Organisations representing patients with NETs should be consulted on all policy and legislation that will affect NETs patients.

VI. Acknowledgements

A policy roundtable was held in the European Parliament in Brussels to mark NET Cancer Day on 10th November. The meeting, chaired by Mrs. Grossetête MEP and Dr. Tannock MEP gathered experts on NETs along with representatives of the European Commission.

The meeting established a commitment to work together at European Union level to ensure the specialist contribution of experts towards European Union policies affecting the NETs community. Addressing the specific issues of rare cancers such as NETs at EU level is considered to provide added-value. Expertise on NETs is scarce, which is why supporting best use of it is essential in Europe.³⁷

It was concluded that the efforts of the group should be divided into the three key issues presented in this paper and that the group will make recommendations, work towards their implementation and reconvene on NET Cancer Day to discuss progress.

DISCLAIMER

The content of this document reflects the discussions and conclusions made during the Expert Policy Roundtable held on the 10th November 2015 in the European Parliament on NETs. The participants, policy makers and other stakeholders contributed to the content of this document also through additional interviews and input provided during a meeting held among the stakeholders earlier on the 10th November 2015. Additional desk research was done by Rohde Public Policy.

This document was edited by Steven Bridges from Rohde Public Policy with the support of Ipsen and Lexicon for meeting costs, layouting and printing. This document was reviewed by the Expert Policy Roundtable participants. Ipsen provided editorial comments to ensure transparency of its support and compliance with applicable rules and laws on the content prior to the finalization of the document by the Expert Group.

The Conclusions and Recommendations within this paper are intended to be used by policy makers, governments and medical community to support improvement in the management and care of NETs.

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- 13 Incidence and prevalence data presented by Prof. Martin Caplin in the European Parliament on 10th November 2015 - Incidence i.e. number of new cases per year 3-5/100,000 population, Prevalence i.e. number living with the disease 20/100,000
- 14 *ibid*
- 15 *ibid*
- 16 Modlin and Gustaffson refer to average of 5-7 years; Massironi to average 3-10 years
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- 19 The International Neuroendocrine Cancer Alliance (INCA) is the global voice in support of neuroendocrine cancer patients. INCA's Mission is to be the global advocate for neuroendocrine cancer patients and its Vision is a world where all neuroendocrine cancer patients get a timely diagnosis, the best care and ultimately a cure
- 20 INCA and Novartis Global NET Patient Survey – November 2014 <http://www.amend.org.uk/research/global-net-survey.html>
- 21 EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare
- 22 EU Regulation No 141/2000 of the European Parliament and of the Council of 16 December 1999 on orphan medicinal products
- 23 Rare Cancers Europe website <http://www.rarecancerseurope.org/About-Rare-Cancers/Families-and-List-of-Rare-Cancers> accessed on December 21 2015
- 24 Summary provided by Dr. Antoine Tabarin - CHU de Bordeaux
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- 34 EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare
- 35 Information provided by INCA <http://netcancerday.org/learn-more/treatment/clinical-research/>
- 36 EU Regulation No 141/2000 of the European Parliament and of the Council of 16 December 1999 on orphan medicinal products
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RECOMMENDATIONS

WARRIOR