

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 • Chairman 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 procedure • 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

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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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