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European Reference Network for rare adult solid cancers, statement and integration to health care systems of member states: a position paper of the ERN EURACAN

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NEWS

European Reference Network for rare adult solid cancers, statement and integration to health care systems of member states: a position paper of the ERN EURACAN



INTRODUCTION

The standard definition of ‘rare cancer’ is a malignant disorder with an incidence of <6 per 100 000 per year according to the Surveillance of Rare Cancers in Europe (RARECARE), with a wide variety of incidence for the different rare cancers.

Rare cancers account, as a whole, for about 20%-25% of all new cancer diagnoses.¹ With the advent of molecular biology and extensive efforts in genomic analyses of cancers (including the International Cancer Genome Consortium, the Cancer Genome Atlas, and the Cancer Genome project, among others), genomic-based classification has contributed over the past few years to identifying rarer molecularly defined subgroups of cancer, and expanding the number of subclasses in many rare cancers.² In Europe, 5-year overall survival rate in patients with rare cancer is 47%, compared with 67% for patients with common cancers.^{3,4} Even after excluding common cancers with good prognosis such as prostate, breast, or skin cancers, the survival difference between rare and frequent tumours remains detectable.

A better understanding of the biology of rare cancers, an improved access to optimal diagnosis, to effective therapies, and to evidence-based treatment guidelines will all improve the outcome of patients with rare cancers. Still, disparities exist across Europe between countries and regions, with heterogeneous patient pathways, and different points of access contacted for initial health care management. Health migration issues also need to be addressed to reduce inequities in care for the European patient.^{5,6}

Among rare cancer experts, a strong consensus exists on the needs of patients with rare cancers to be referred from the first steps of diagnosis to certified reference centres, in order to benefit from the most up-to-date experience and multidisciplinary organizations to ensure appropriate care to all patients, regardless of the initial point of access.⁷⁻¹⁶

Building on previous policy statements and guidelines, and considering the unfulfilled needs of patients with rare and low-prevalence cancers, this position paper was initiated to discuss important topics to improve the management of rare cancers within the ERN, focusing on (i) the integration of European Reference Networks (ERNs) within the national health care systems, while national networks are in parallel integrated within the ERN activities, (ii) the continuous development of collaborations and networking of national reference centres with institutions and organizations at a pan-Europe scale contributing to ERNs, and (iii) increased knowledge and data sharing to continuously improve

management of patients with rare cancers from the date of diagnosis and throughout the continuum of disease.

OBJECTIVES

The present document was composed to comment on the ERN Board of Member State statements issued in June 2019 about the integration of the ERNs into the health care systems of member states.¹⁷ This document lists prioritized potential actions considered as relevant by the Members of the Working Group for the planning and implementation of sustainable integration processes.¹⁸ The EURACAN national representatives carried out an extensive review of the document per item, and discussed each issue in detail, with the aim of better understanding how the implementation can be put into actions in the different European countries. The EURACAN group collectively proposed recommendations for the future for effective application. Some may be specific to this ERN considering the diversity of rare cancers and their total numbers. Others can be common to all ERNs. A summary of the comments, proposals, and unanimous recommendations from EURACAN members attending the meeting organized in Paris on 6 February 2020 is presented below. This publication aims to share the feedback of the EURACAN stakeholders, doctors, and patients from the rare cancer world [health care providers (HCPs) and European patient advocacy groups (ePAGs)] on what is needed to ensure the success of this and other ERNs. This article is addressed to the whole health care community, to all stakeholders engaged in the care of rare cancers (and rare diseases), as well as to European Union (EU) and national policy makers, with the hope it may provide a useful feedback to ensure the success of ERNs, which are important projects for the whole of Europe.

THE ERNS INCLUDING THOSE DEDICATED TO CANCERS

The first 24 ERNs listed in [Table 1](#) started their activities in 2017 with a 5-year support of the EU Health Programme and have included 300 hospitals and 900 health care units.

ERNs are networks of expert reference centres for rare medical conditions, bringing together HCPs with documented expertise across all countries in Europe. Their missions are to increase the quality of routine care of patients with rare cancer, to increase awareness and promotion of education, and to develop educational tools and promote the generation of research programs. The final objective is to ensure that patients will access the best, most up-to-date care across Europe in the specific case of rare disease.

There are four ERNs dedicated to cancer: PaedCan for paediatric cancers, EuroBloodnet for haematological malignancies, GENTURIS for cancer predispositions, and EURACAN for rare adult solid cancers ([Table 1](#)).

The ERN EURACAN includes 10 domains corresponding to the list of rare adult solid cancers (RARECARE) based on the International Classification of Diseases: connective tissue,

female genital organs and placenta, male genital organs and urinary tract, neuroendocrine system, digestive tract, endocrine organs, head and neck, thorax, skin cancers and eye melanoma, brain tumours and spinal cord) and sub-thematic areas (Figure 1).

As of January 2021, EURACAN gathers 66 HCPs full members across 17 European countries, 9 affiliated partners across 7 more member states with expertise specifically matching the global thematic domain of EURACAN, and 30 associated partners (ePAGs, rare disease stakeholders). Associated partners, along with patient advocacy groups, scientific societies (e.g. European Society for Medical Oncology), education societies (e.g. European School of Oncology), and research consortia (e.g. *European Organisation for Research and Treatment of Cancer*, EORTC) are participating in the activities of the ERN and often lead transversal activities (www.euracan.eu, Figure 2). HCPs were identified on the basis of documented expertise, accrual in rare cancers, and endorsement by their member states. Each domain is managed by a domain leader. Transversal task forces dedicated to transversal tasks across tumour domains (guidelines, communication, research, etc.) were developed with a matrix format including all domains and domain representatives, led by experts from HCPs or associated partners. They all belong to the EURACAN Steering committee. The governance structure is described in Figure 3. New candidate applications are being reviewed and may increase the number of centres up to 106 HCPs across 26 countries within 2021. The objectives of the ERN EURACAN are mentioned in the recommendations hereunder, and listed in Table 2.

STATEMENT OF ERN BOARD OF MEMBER STATES: INTEGRATION OF THE ERNS TO THE HEALTH CARE SYSTEMS OF MEMBER STATES

After 2 years of existence, it appeared that the integration of the ERN in the different health care systems was an essential step to ensure their capacity to develop their missions. In this perspective, on 25 June 2019 the ERN Board of member states adopted a new statement concerning recommendations and good practices to foster integration of the ERNs in national health care systems.¹⁷ In order for the ERNs to reach their full coverage potential and offer fair access possibilities to all patients, ERNs must be linked in a clear and sustainable way to all national health care systems. To support the action of member states in this direction, the ERN Board of member states approved a statement which provides guidance and examples of good practices to encourage national authorities to put in place measures to integrate the ERNs in their national health systems. This statement of the ERN Board of member states includes five intervention issues on (i) links with national policy and/or legal framework, (ii) patients' pathways, (iii) referral to ERNs, (iv) strategy for communicating and disseminating information, (v) global support to the ERNs. An annex to the statement presented a non-exhaustive list of prioritized potential actions identified as relevant by the

Table 1. European Reference Networks (ERNs)	
Endo-ERN	European Reference Network on endocrine conditions
ERKNet	European Reference Network on kidney diseases
ERN BOND	European Reference Network on bone disorders
ERN CRANIO	European Reference Network on craniofacial anomalies and ENT disorders
ERN EpiCARE	European Reference Network on epilepsies
ERN EURACAN	European Reference Network on adult cancers (solid tumours)
ERN EuroBloodNet	European Reference Network on haematological diseases
ERN eUROGEN	European Reference Network on urogenital diseases and conditions
ERN EURO-NMD	European Reference Network on neuromuscular diseases
ERN EYE	European Reference Network on eye diseases
ERN GENTURIS	European Reference Network on genetic tumour risk syndromes
ERN GUARD HEART	European Reference Network on diseases of the heart
ERNICA	European Reference Network on inherited and congenital anomalies
ERN ITHACA	European Reference Network on congenital malformations and rare intellectual disability
ERN LUNG	European Reference Network on respiratory diseases
ERN PaedCan	European Reference Network on paediatric cancer (haemato-oncology)
ERN RARE-LIVER	European Reference Network on hepatological diseases
ERN ReCONNET	European Reference Network on connective tissue and musculoskeletal diseases
ERN RITA	European Reference Network on immunodeficiency, autoinflammatory and autoimmune diseases
ERN-RND	European Reference Network on neurological diseases
ERN Skin	European Reference Network on skin disorders
ERN TRANSPLANT-CHILD	European Reference Network on transplantation in children
MetabERN	European Reference Network on hereditary metabolic disorders
VASCERN	European Reference Network on multisystemic vascular diseases

ERN Board of member states for the planning and implementation of sustainable integration processes.¹⁸

DISCUSSION, COMMENTS AND RECOMMENDATIONS BY EURACAN REPRESENTATIVES ON THE ACTIONS PROPOSED IN THE ERN BOARD OF MEMBER STATES

We present here the comments of the EURACAN group on actions proposed in this document. The principal recommendations are also presented on Table 3.

1. National rare disease plans/strategies and legal framework for ERN integration
 - Inclusion of ERN coordinators and/or ERN members/affiliated partners into policy-making bodies (e.g. those responsible for a national plan or strategy adoption/implementation/monitoring) or realize another way to involve their expertise into policy making.

Situation. There is an important variability in the structures in place to take care of rare cancer patients across countries, and in the interactions of ERN members with national policy makers.



Figure 1. Rare adult cancers.

Thematic and sub-thematic area.

EURACAN, the European Reference Network for rare adult solid cancers.

Recommendations. National policies should ensure that rare cancer patients have access to expert centres and benefit from their actions. EURACAN centres in all countries should be made more visible either for patients or within rare cancer networks in all countries. ERNs, through national representatives designated by the countries within the reference centres, should be connected to policy-making bodies in all member states, in order to ensure their integration in the making of cancer plans and rare cancer plans. The creation of an *ad hoc* committee for ERNs, in this case for EURACAN, within each Health Ministry (involving both health care professionals and ePAGs or patient representatives), is required to ensure the best integration of the ERN action in the strategy of each Member state with two meetings a year. This recommendation is a priority and is proposed for the short term.

- Commitment to engage into ERNs through any possible kind of membership or affiliation.

Situation. The designation or endorsement procedure for the participation of an HCP in the ERN EURACAN appears to vary across member states. This was observed for all

individual cancer domains within EURACAN. Importantly, ePAGs underlined that experts of a given country for their rare disease were not systematically involved in the ERN, and ERN members of a given country did not systematically have the expertise in all rare diseases covered by the ERN. Depending on the country, treatments are provided by designated centres, certified centres, or recognized centres, or can be delivered in any centre.

Recommendation. A homogeneous and more exhaustive identification process is needed to ensure consistency across countries and at the EU level. The above-mentioned national *ad hoc* committee for EURACAN may have the role of identifying and proposing the integration, inclusively, of internationally and nationally recognized expert national teams for all rare cancers, to ensure the proper representation of the country in the ERN. Here again, this recommendation is a priority and is proposed for the short term.

- Clear and if necessary legally defined procedures for the endorsement of centres of expertise for the ERN membership and/or designation of Affiliated Partners to the ERNs.

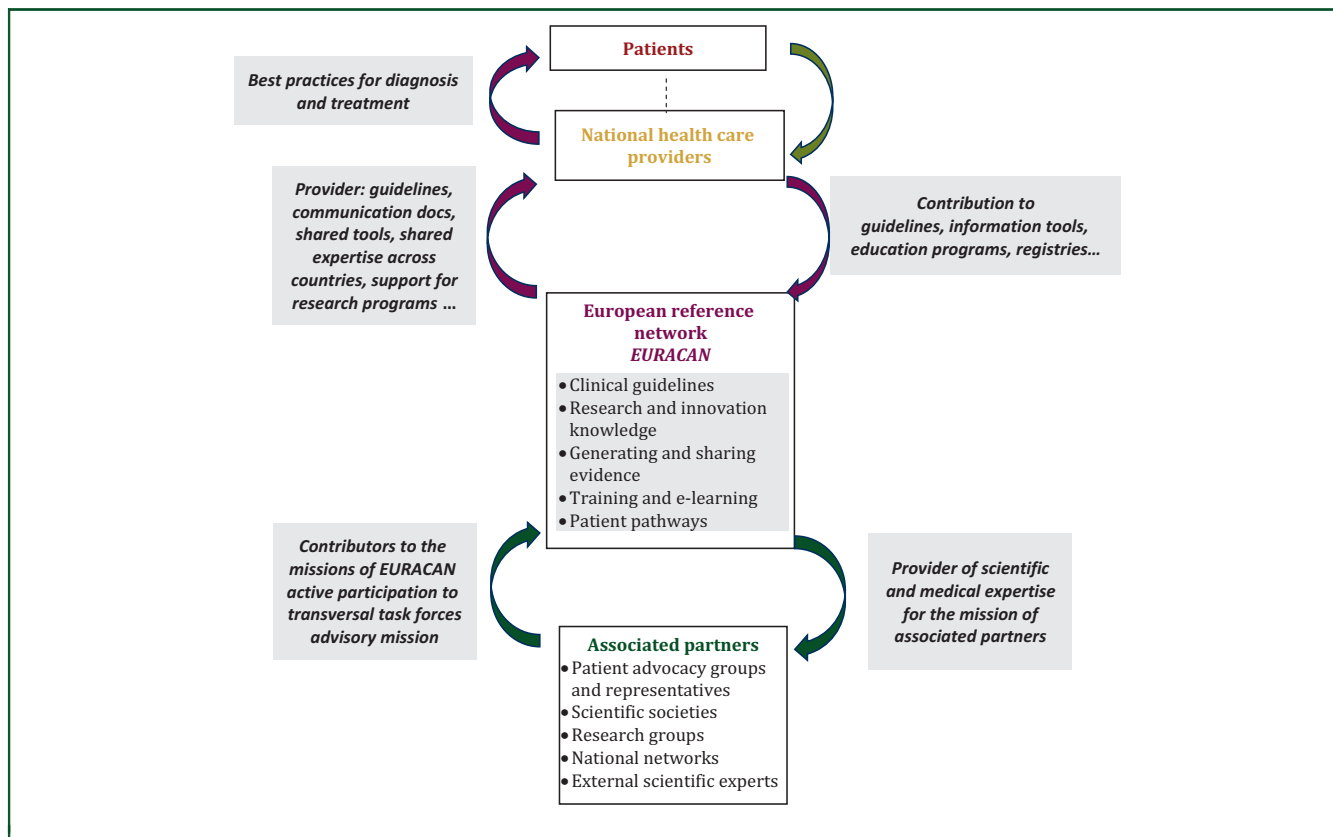


Figure 2. Schematic representation of national health care provider (HCP) and EURACAN interactions for optimal patient management through shared expertise regarding diagnosis and treatment.
EURACAN, the European Reference Network for rare adult solid cancers.

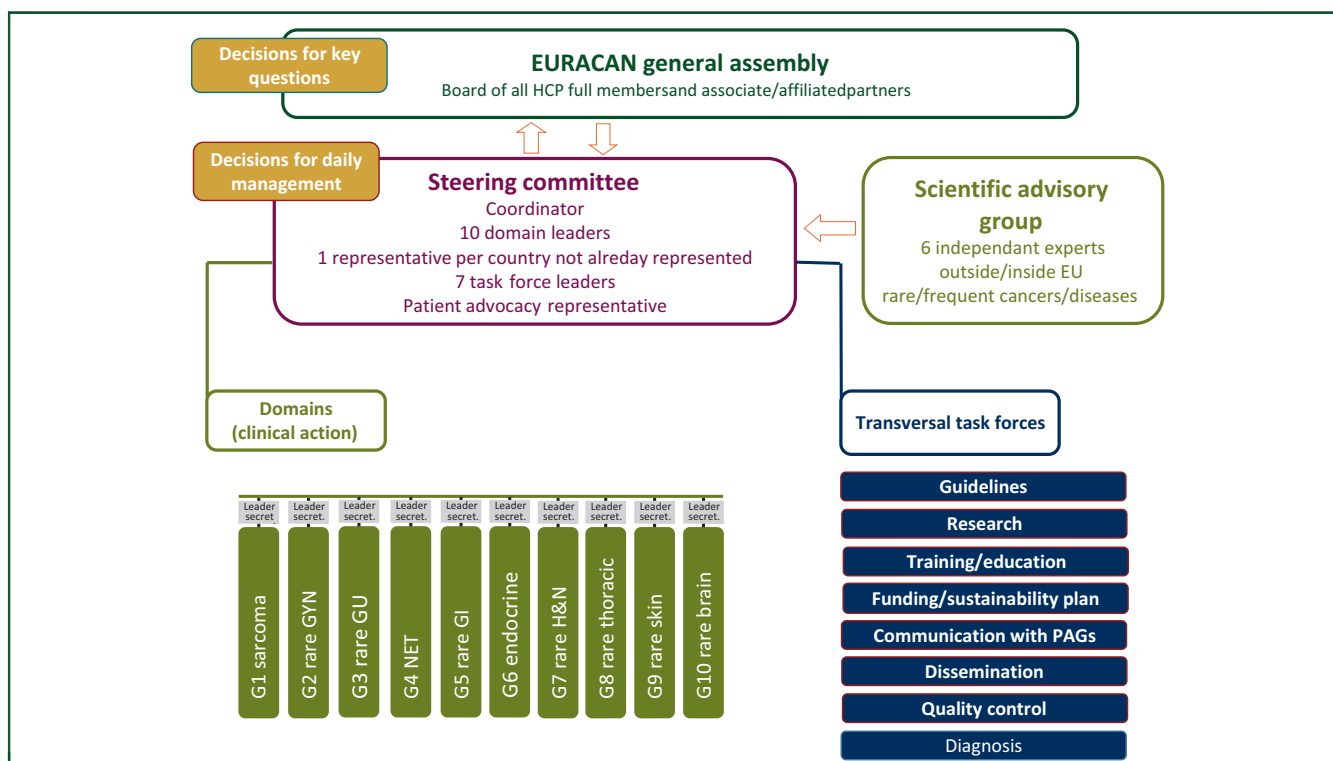


Figure 3. EURACAN Governance.
EU, European Union; EURACAN, the European Reference Network for rare adult solid cancers; GI, gastrointestinal; GU, genitourinary; GYN, gynaecological; H&N, head and neck; HCP, health care provider; NET, neuroendocrine tumour; PAG, patient advocacy group.

Table 2. The objectives of EURACAN-ERN for rare adult solid cancers

- To increase access to accurate pathological and molecular diagnosis of rare cancers.
- To improve access to optimal standard treatments as well as innovation across all EU member states.
- To develop training programmes for medical teams in all countries to increase and harmonise the quality of care for rare cancers.
- To integrate patient advocacy groups for the construction and dissemination of the work of the network as well as for educational tools.
- To implement 'roadmaps' for referral and self-referral of patients to expert centres.
- To develop and continuously review Clinical Practice Guidelines (CPGs).
- To interact with key national and international actors/networks involved in cancer care and research and beyond, with other rare diseases stakeholders.

ERN, European Reference Network; EU, European Union; EURACAN, the European Reference Network for rare adult solid cancers.

- Clear and if necessary legally defined procedures for the identification and designation of national centres of expertise.

Situation. Dedicated reference centres are already active and accruing rare cancer patients in most countries. The process of identification of reference centres, affiliated centres, and national centres of expertise, however, varies across countries.

Recommendations. The leading institution could systematically be proposed as candidate members for all ERNs. Similar criteria should be used across countries to identify centres as full or affiliated ERN members across countries. In the short term, a more consistent process, or set of criteria, should be proposed for the definition and identification of reference centres across countries, obviously adapted to the specificities of the health care system, to the population of the country, etc. Rare cancer networks are already identified in some countries; they should be connected to the ERN. In addition, an accreditation process including patient satisfaction surveys, yearly reports, and official formalization (belonging to EURACAN network) must be explored, when budgets enable the full deployment of ERN actions. For this, cross-evaluation between centres could be considered to ensure that patients with rare cancer will be appropriately referred to reference centres. The evaluation process of the ERN performance is an important goal for the mid to long term, but should take place after sufficient time and financial support were given to enable their missions and actions.

- Clear and transparent procedural organization and/or where possible and appropriate, a legal definition of other ERN integration-related procedures and processes, e.g. care pathways, clinical networks, referral systems, interregional collaboration in care pathways, accreditation/certification/monitoring of centres of expertise/ERN Members, use of clinical patient management systems (CPMS) and patients' data management, adoption/implementation of ERN-developed evidence-based resources for clinical practice, medical education on rare diseases, etc.

Situation. Despite an important work of all, the present version of the CPMS is not adapted to the volume of

Table 3. Recommendation of the EURACAN members to better integrate European Reference Networks EURACAN to the health care systems of member states

- Adoption of the EURACAN Clinical Practice Guidelines for rare cancers in all EU countries.
- Creation of a country *ad hoc* committee in charge of interaction of national policy makers with EURACAN
- Integration of national experts for all rare cancers in the national *ad hoc* committee.
- Integration of patient representatives in the *ad hoc* committee.
- Shared methods and criteria for the designation of HCPs for all countries.
- Designation of rare cancer networks or reference centres for rare cancers in all countries.
- Consistent patient pathways to refer rare cancer patients to the reference centre of his own country.
- Identification of criteria for cross-border health care.
- Simplification of cross-border health care when criteria are met.
- Developing alternative or simplified methods for international MDTs beyond CPMS.
- Financial support for rare cancer network in each health care system.
- Increase EU financial support for core missions of EURACAN (registries etc.).

CPMS, clinical patient management systems; ERN, European Reference Network; EU, European Union; EURACAN, the European Reference Network for rare adult solid cancers; HCPs, health care providers; MDTs, multidisciplinary teams.

activity of management of rare adult cancers, but can be used for very unusual presentations.

Recommendations. Allowing the ERNs to develop an adapted methodology in view of the specificities of their patient population is essential. This task should involve the above-mentioned *ad hoc* committees and should allow a flexible approach for the definition of the procedures depending on the ERN, the nature of the disease treated, as well as the number of patients. As an example, in the case of adult patients with rare cancer, accounting for 540 000 new cases per year (20% of the 2.7 million new incident cancer cases in the EU),¹⁹ the use of time-consuming tools such as CPMS is not feasible for all patients, and may be reserved for specifically complex situations, leaving more flexible approaches for the majority of patients. Other systems should be made possible to serve larger populations of patients.

2. Patient care pathway

- Organization of national care pathways to ensure centre of expertise/ERN accessibility with the aim of getting a timely diagnosis and instituting appropriate treatments in rare and complex diseases.

Situation. There are disparities between countries for the organization and the definition of 'care pathway' for the standard process from diagnosis to treatment to comply with ERNs and their guidelines.

Recommendations. To create reference centres and networks for all rare cancers in all countries, and recommend a centralized pathology review and early referral to reference centres which demonstrated improved patient outcome. This is a short to long-term recommendation depending on the health care system. The output of successful national organizations, with a compulsory referral process, including clear timelines, as implemented in some countries, can be used as guidance.

- Multidisciplinary approach and horizontal integration of services in the centres of expertise.

Situation. The multidisciplinary methods within the different HCPs need to be more precisely defined. Structured multidisciplinary board meetings exist but operate in different ways from one country to another (scheduled at different stages, with different objectives, etc.)

Recommendations. ERNs must develop flexible approaches to define how multidisciplinary board meetings should be managed in different health care systems (what form, who signs the report, what additional information should be used and communicated). While CPMS may be suitable for specific tasks, it may be too demanding for a large number of patients as encountered in large reference centres on a weekly basis. The adaptation to different health care systems is also an important issue and this task may be given to the *ad hoc* committees already mentioned above, as a task for the mid-term.

- Care coordination for patients with rare and low prevalence complex diseases.

Situation. Patient coordinators exist in a many but not all centres; they should be available in every expert centre. Nurse coordinators exist in most centres; they could become compulsory to best serve the ambitions of the ERNs.

Recommendation. A (group of) coordinating nurse should be involved actively in all ERN EURACAN centres, for each of the 10 predefined domains for rare cancer.

- Monitoring of centres of expertise and/or care pathways for constant improvement.

Situation. The nature of the monitoring is unclear; quality outcome is not precisely defined nor are the procedures to be taken if quality outcomes are not reached in a specific ERN centre. Concern about how quantified data will be used for accreditation was expressed. It was also emphasized that an appropriate monitoring of centres can take place only when financial support of adequate magnitude has been provided to fulfil the missions of the ERN centre.

Recommendations. Adequate support must be given to the ERN centres to enable the action, which cannot be achieved without adequate resources. National accreditation processes must be implemented by national health authorities. Periodic intra ERN audits by other centres with the supervision of domain leaders could be carried out in order to measure quality with a peer system and to reinforce interactions within the ERN. Self-declaration should be explored, as well as cross centre evaluation within an ERN.

Audit by ePAGs will also need to be considered. These are recommendations for the mid to long term and require first that appropriate funding is provided to the HCP and for all ERN.²⁰

- Where appropriate, to foster interregional collaboration in care pathways to ensure centres of expertise/ERN accessibility and diminish unwarranted interregional differences in care provision for rare and complex diseases.

Situation. Collaboration for patient pathways across borders is marginal and has just started. Conversely, there are examples of active networks already in place, which enable intranational and interregional collaborations for care pathways. Measures are needed, and for this, collaborations for the creation of a common tool, registries for all rare cancer patients, across countries (such as The STARTER project) have started. Funding registry programs to sufficient levels are needed to ensure interactions.

Recommendation. EURACAN will implement recommendations on patients' referral, but it is premature to assess progress at this early stage of network development, and while the process of cross-border health care is not stabilized. The measure and quantification of the action of the centres in the different regions is the first step of the process. Differences across regions must be measured, before corrections can be applied. Establishing registries for all rare cancers is needed, with prospective collection of disease/tumour management and outcome. For this it is essential to ensure adequate funding. This is a priority for the short term.

- Vertical integration of services and transitions of care in care pathways.

Situation. These suggestions are linked to care coordination. The care pathways for appropriate referral to a centre (way in and way out) are not consistently defined.

Recommendations. The EURACAN team again recommend here the creation of reference networks in large countries with hitherto no reference networks to disseminate the production of the ERN EURACAN at the regional level, the mandatory referral to the centres belonging to these networks, and the implementation of a national strategy (adapted to the health care system) to provide guidance on how non-specialized hospitals should proceed to appropriately refer patients.

- To reconsider national Clinical Practice Guidelines and Clinical Decision Support Tools for efficient diagnostic pathways that include ERNs.

Situation. The majority of countries have national guidelines, often based on the adaptation of international guidelines such as those quoted in the references.¹²⁻¹⁶

Recommendations. EURACAN guidelines should be adopted at the national level for all member states and constitute the basic frame for further implementation all across Europe to provide a uniform state of the art at the EU level. National guidelines made understandable by patients should be provided. These are recommendations for the short term which are simple and would have a major impact.

3. Referral systems to the ERNs

- Alignment of national care pathways with ERN referral systems to ensure ERN accessibility according to the needs of member states.

Situation. National care pathways are not consistently aligned across countries.

Recommendation. A key issue is to make known and available the existence of ERNs with a dedicated referral

pathway per country. The starting point is the referral to a reference centre. Earlier referral from general practitioners (GPs) or national groups should be developed, and ERN articulation with national network/cooperative groups and scientific societies must be enhanced. With a careful adaptation to the specificity of the national health care system, the GPs and primary cancer centres should be informed of the ERN structures and processes and guided for the contact to the entry point in each country.

- To foster national and cross-border IT tools and procedures to ensure safe and general data protection regulation—compliant exchange of patients' data for ERN-related services.

Situation. As of now, cross-border health care is not systematically organized within EURACAN. EURACAN centres are contacted directly by patients or medical teams, who identify their contact directly or with the help of EURACAN sites. Approval of cross-border health care is variable across member states.

Recommendation. It is essential, at the national level, in connection with the ERN, to define the situations for referral, to simplify the tools for exchange, facilitate, accelerate, and allow/reimburse direct access to centres using a simple, transparent, and flexible system. This is one of the tasks of the *ad hoc* national committee for the mid-term.

- Establishment of a national network of ERN Members and/or affiliated partners to ensure ERN accessibility to address the needs of member states.

Situation. As already mentioned, not all countries have identified reference centres, and/or national networks of experts for rare adult cancers.

Recommendation. This task will be ensured by the national *ad hoc* committees mentioned above.

- Establishment, at national/regional level, of networks of disease groups covered by ERNs in order to ensure smooth patient access to ERN services if and when necessary.

Situation. As mentioned above, there is a lack of national networks for rare cancers covered by EURACAN in some member states.

Recommendations. The recommendation is to formalize links with all structured national networks, and support the development of such national networks if not existing. EURACAN can also be seen as the network of national networks, connected through the head of national networks. National referral should obviously always prevail and must be built on the national networks, leaving international referral for situations where national expertise is not yet available.

4. Information on ERNs provided at member state level The assembly initiated general discussion on key area 4 and made recommendations for actions.

- Strengthening dissemination of information on ERNs, national care pathways, referral systems, and health system organization for rare and complex diseases among medical, nursing, and allied health professionals according to the needs of member states.

- Promoting medical education on rare and complex diseases.
- Strengthening dissemination of information to and increasing awareness of the general public on ERNs according to the needs of member states.
- Supporting communication and coordination between the different stakeholders involved in the care provision for rare and complex diseases.

The EURACAN group strongly recommends increasing the visibility of networks of rare cancers in each country by reinforcing national communication, working with the national *ad hoc* committees.

Several aims must be considered, and the following recommendations were proposed:

- At short term:
 - Strengthening dissemination of information on ERNs, national care pathways, referral systems, and health system organization for rare and complex diseases among medical, nursing, and allied health professionals according to the needs and structures of health care systems of all member states.
 - Promoting the dissemination of information to the general public on ERNs according to the needs of member states, to increase awareness on the ERN structures.
 - Supporting communication and coordination between the different stakeholders involved in the care provision for rare and complex diseases.
- At mid-term:
 - Promoting medical education on rare and complex diseases at different stages of medical training.

5. Support by member states to ERN coordinators, ERN member states, and affiliated partners.

The assembly initiated general discussion on key area 5 and made recommendations for actions.

- Support (that may, inter alia, be administrative, financial, organizational, informational) to ensure sustainability at the national level of ERN members and/or affiliated partners.
- Develop an environment that allows ERN coordinators and/or ERN members to accept the support provided by the European Commission.
- Aim at tackling unnecessary and wasteful spending in the care of rare and complex diseases.
- Identify and address HCP specific needs to enable efficient participation in ERN activities.

Recommendations. They are in line with the above-mentioned recommendations.

It will be important to formalise the commitment of EURACAN national representatives in the above-mentioned national *ad hoc* committees in the short term, with the aim to promote networking in health care policy system, with implementations adapted according to the different countries and health care systems.

- With regard to the sustainability of networks, issues need to be addressed also at a national level; the allocation of dedicated budgets and extra-budgetary resources adapted to the system will be an important element to ensure the dissemination of the work of the ERNs.
- The mobilization of ePAGs to lobby their governments to support financially expert centres, members of an ERN.
- Next, EU framework programmes should provide stronger ERN support and funding.
- Rare cancers should be included systematically in the European Joint Program for Rare Diseases' funding and calls.
- Additional funding to support a multidisciplinary approach, or to request second opinions across borders, should be provided
- Emphasize the need for dedicated specialists, strengthen the expertise in rare cancers.
- Emphasize the support of member states to improve ERN communication and visibility.
- Use the demonstrated savings in health care costs to finance the activities of the rare cancer networks.

The patient representatives have a key role in the development of ERN EURACAN actions. The analysis and proposed recommendations listed above are consistent with their recommendations, highlighting the value of the interaction of the ERN with ePAGs as associate partners. The EURORDIS recommendations on the integration of ERN into the national health system were published in 2018²⁰ and recommended the following actions.

- (i) Create a good level of awareness at a national level of the ERN model among all key stakeholders.
- (ii) Ensure political leadership and ownership of the ERN system at national level and generate sound evidence on the value of the ERN model.
- (iii) Review or adapt national policies on rare or low prevalence and complex conditions to address integration of ERNs into the national health systems.
- (iv) Member states to set up national networks of rare disease expert centres and the rare disease patient community to create national networks compatible with the ERN disease groupings.
- (v) Incorporate new full members and affiliated partners specifically to cover the geographical and/or expertise gaps of ERNs.
- (vi) Set up national coordination hubs and designate ERNs national focal points.
- (vii) Streamline the process to endorse HCPs that apply for full membership.
- (viii) Define and validate ERN referral pathway at national level to ensure timely access to ERNs advice and adequate management of case referrals.
- (ix) Establish a funding mechanism to finance the virtual advice from ERNs.

- (x) Develop a mechanism to recognise and adopt at national level clinical guidelines reviewed or adopted by ERNs.

These recommendations are supported unanimously by the EURACAN investigators.

In conclusion, the rare adult solid cancers network EURACAN provides access to European HCPs with expertise in several rare malignancies through a multi-tumour integrated multinational network, centralizing knowledge and experience in clinical practice, medical research, educational programmes, and led to the establishment of transverse task forces in the 10 domains. As suggested by the ERN board of member states in their recent report, and as previously mentioned by patient advocacy groups, it is essential to better connect the ERNs, and in particular EURACAN, to the national health care systems, considering local specificities and appropriately adapted to accommodate those specificities.²¹ This ERN should act as a network of networks at the national and international level to provide timely, accurate diagnosis and more appropriate treatment to European patients, and unify and optimize access to the most up-to-date clinical practices in the EU. The members of EURACAN, the different national representatives, proposed here a set of recommendations which could provide a decisive input for the success of the missions of this ERN dedicated to rare adult cancers, and the potential ability to be extrapolated to other ERNs. The expansion of the number of centres in July 2021 will also enable expansion of the action of EURACAN. Because of their uniqueness as a bond across the health care systems of the member states, the ERNs are an opportunity to transform the care of EU patients. And all together, we must succeed.

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DISCLOSURE

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