

# Mapping the existing National networks of care for rare cancers

## JARC WP5.1



*“This Deliverable is a part of the joint action “724161/JARC” which has received funding from the European Union’s Health Programme (2014-2020)”.*

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## JARC WP5.1

**Prepared by:**

Harriët Blaauwgeers, Annemiek Kwast, Jan Maarten van der Zwan, Simon Oberst, Annalisa Trama

**Organisation**

Joint Action on Rare Cancers (JARC)

Grant Agreement No. 724161

Work Package No. 5  
Assuring Quality of Care

Deliverable No. 5.1



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# 1 Summary

This report WP5.1 of the Joint Action on Rare Cancers aims to map the existing networks of care for all 11 families of rare adult cancers, across all Member and identifying gaps in current scenarios.

To map the existence of cancer care networks a questionnaire was sent to the 28 Member States.

Thereafter, to have more clarity on the information provided in this questionnaire, interviews were performed.

Out of 23 respondents (Annex 1) who filled in a questionnaire on the existence of cancer care networks the following results are found:

- 15 Member States have general cancer care networks organised on a national and/or regional level (65%);
- 2 Member States have a general cancer care network for rare cancers (9%). These Member States also have general cancer care networks;
- 14 Member States have tumour specific networks on rare cancers (61%);
  - Networks for sarcomas are most common (12 Member States)
  - Networks for rare cancers in the Thorax are the least common (6 Member States)
- 7 Member States have no cancer care networks at all (general, rare cancers, rare cancers tumour specific) (30%).

In conclusion:

- Not in every Member State networks of care for (rare) cancers are established.
- The organisation of the cancer care networks can differ among the Member States.
- Due to lacking of a rare cancers network in a Member State, the insurance for rare cancer patients to have access to the expertise available throughout their Member State is lacking. Also, the insurance of the integration of the ERN within the MS is lacking.
- Tumour specific cancer care networks for rare thorax tumours are the least common organised in the Member States. In 6 Member States (26%) networks for rare thorax tumours are organised
- Cancer care networks for sarcomas are available in 12 Member States (53%) which the most common tumour specific network.
- There is a difference in organisation of (rare) cancer care networks between the Member States.

## 2 Description

### 2.1 Joint Action on Rare Cancers

The Joint Action on Rare Cancers (JARC) is aimed to integrate and maximize efforts of the European Union (EU) Commission, EU Member States and all stakeholders to advance quality of care and research on rare cancers.

The public health challenges posed by rare cancers include the limited professional expertise in the community, the difficulties in clinical research, the need of a timely and appropriate diagnosis and optimal treatment from the very beginning of the patient's journey. An accurate clinical, pathologic and biological assessment of the disease of the individual patient is key to survival and cure, as well as an expert clinical decision provided by a multidisciplinary team. To this end, proper referral of patients and effective clinical networking are crucial in rare cancers. This is the main reason why JARC decided to shape its efforts around the new European Reference Networks (ERNs) with the following objectives:

- 1 Improving epidemiological surveillance of rare cancers in the EU
- 2 Identifying standards of care for all families of rare cancers to ensure sharing of best practices and equality of care for rare cancers across Europe, particularly through clinical networking
- 3 Improving the implementation at local level and within ERNs of clinical practice guidelines on rare cancer
- 4 Promoting integration of translational research innovations into rare cancer care
- 5 Improving education on rare cancers for medical and non-medical experts to ameliorate management of rare cancers and to improve rare cancer patients' empowerment in the EU
- 6 Identifying core strategies to incorporate in National cancer plans and Rare disease plans to address the specific needs of rare cancers across EU MSs

The JARC is structured in 10 work packages (WPs). Three cross cutting WPs (WP1 coordination, WP2 dissemination, WP3 evaluation) and 7 specific WPs based on the JARC objectives: WP4 epidemiology, WP5 quality of care, WP6 clinical practice guidelines, WP7 innovation and access to innovation, WP8 medical education, WP9 childhood cancers and, WP10 rare cancers policy. Patients work across all work packages, driving the JARC efforts along the needs of the only end users of all what we can do, in care and research as well.

### 2.2 Description of WP5 Assuring Quality of Care

This WP aims to design healthcare quality assurance systems or processes specific to the 11 major families of rare cancers to add to the ERN requirement. Childhood Cancers already covered by ExPO-r-Net project.

### 2.3 The aim and the purpose of the deliverable WP5.1

Map the existing networks of care for all 11 families of rare adult cancers, across all Member States (expanding the exercise carried out by EPAAC WP7 and RARECAREnet) and identifying gaps in current scenarios.

### 2.4 The target group of the deliverable

Policy makers and ERN coordinators. This WP providing an overview of the networks for rare cancers available at country level will allow identifying countries where national networks should be established. It will provide the basis for future discussion about the integration of the ERN within the national health care system. Finally yet importantly, it will provide data to patients to advocate for the establishment of networks for rare cancers.

## 2.5 Summary of the main results

Out of the 23 respondents (Annex 1) who filled in the questionnaire on the existence of cancer care networks:

- 15 Member States have general cancer care networks organised on a national and/or regional level (65%);
- 2 Member States have a general cancer care network for rare cancers (9%). These Member States also have general cancer care networks;
- 14 Member States have tumour specific networks on rare cancers (61%);
- Networks for sarcomas are most common (12 Member States);
- Networks for rare cancers in the Thorax are the least common (6 Member States);
- 7 Member States have no cancer care networks at all (general, rare cancers, rare cancers tumour specific) (30%).

## 2.6 Conclusions

- Not in every Member State networks of care for (rare) cancers are established.
- The organisation of the cancer care networks can differ among the Member States.
- Due to lacking of a rare cancers network in a Member State, the insurance for rare cancer patients to have access to the expertise available throughout their Member State is lacking. Also, the insurance of the integration of the ERN within the MS is lacking.
- Tumour specific cancer care networks for rare thorax tumours are the least common organised in the Member States. In 6 Member States (26%) networks for rare thorax tumours are organised.
- Cancer care networks for sarcomas are available in 12 Member States (53%) which the most common tumour specific network.
- There is a difference in organisation of (rare) cancer care networks between the Member States.

## 3 Introduction

Each year in the EU, around 640,000 people are diagnosed with rare cancers (24% of all cancers diagnosed in EU28).

Patients with a rare cancer pose the typical challenges of rare diseases and those of cancer. Due to the low volume, which is inherent to the rarity of the cancer, limited professional expertise is available and only a few clinical trials exist. This while there is an urgent need of a timely and correct diagnosis and optimal treatment from the very beginning of the patient's journey. An accurate clinical, pathological and biological assessment of the rare cancer is key for patients' survival chances and optimal quality of life. As well as the need for expert clinical decision making provided by a multidisciplinary team. To this end, referral of patients into an effective clinical network is crucial in rare cancers. The goal of the JARC is to contribute to improve health outcomes for patients with rare cancers in the EU and to decrease health inequalities across EU countries. Strategically, maximizing chances of ERNs and national networks on rare cancers to be successful is seen as a key factor.

Work Package 5 (WP5) aims to identify standards of care for rare cancers clinical networks to ensure best practice and quality of care for patients with a rare cancer across Europe, particularly through clinical networking. All 11 families of adult rare cancers that follow their own patient pathway are singled out (Childhood Cancers already covered by ExPO-r-Net project):

- 1 Head and neck cancers (cancers of nasal cavity and sinuses, nasopharynx, hypopharynx, larynx, salivary glands, oropharynx, oral cavity and lip, eye, middle ear).
- 2 Thoracic rare cancers (tumours of trachea, thymus, malignant mesothelioma).
- 3 Male genital and urogenital rare cancers (tumours of testis, penis, renal pelvis, ureter, urethra, and extragonadal germ cell tumours).
- 4 Female genital rare cancers (tumours of vulva and vagina, non-epithelial tumours of ovary, trophoblastic tumours of the placenta).
- 5 Neuroendocrine tumours.
- 6 Tumours of the endocrine organs (cancers of thyroid, parathyroid, adrenal cortex, pituitary gland).
- 7 Central Nervous System tumours (Glial tumours, medulloblastoma, malignant meningioma).
- 8 Sarcomas (soft tissue sarcomas, bone sarcomas, gastrointestinal stromal tumours).
- 9 Digestive rare cancers (Tumours of small intestine, anal canal, gallbladder and extrahepatic biliary duct).
- 10 Rare skin cancers and non-cutaneous melanoma (melanoma of mucosae and of the uvea, adnexal skin carcinomas, Kaposi sarcoma).
- 11 Haematological rare malignancies (acute myeloid leukemia, myeloproliferative neoplasms, myelodysplastic and myeloproliferative neoplasms, histiocytic and dendritic cell neoplasms)

In order to promote standards for rare cancer care networks, it is important to understand the current state of the existing national and/or regional cancer care networks for all 11 families of adult rare cancers in all EU Member States. Therefore, the following objective was defined:

### **Objective JARC WP 5.1**

Map the existing networks of care for all 11 families of rare adult cancers, across all Member States (expanding the exercise carried out by EPAAC WP7 and RARECAREnet) and identifying gaps in current scenarios.

## 4 Methods

The mapping of the existing networks of care for all 11 families of rare adult cancers was organised in 2 phases.

### 4.1 Phase 1: Development of a questionnaire

A short questionnaire was developed by the members of WP5. This questionnaire existed out of four simple questions to identify the relevant Member States for further investigation.

Questions:

- 1 Is there a national comprehensive cancer care network similar to the CanCon definition provided?
- 2 Are there regional comprehensive cancer care networks similar to the CanCon definition provided?
- 3 Is there a national or regional comprehensive cancer care network for rare cancers in general similar to the CanCon definition provided?
- 4 For which of the following (families) of rare cancers does a national or regional tumour specific network(s) exist in your country similar to the CanCon definition provided?

National are distinguish from regional networks, because in Member States the cancer care is organised at regional and/or national level. The definition of a Comprehensive Cancer Care Network (CCCN) provided by the CanCon project was used to have a common reference. The CanCon definition of CCCN is one of the few definitions focusing on the provision of comprehensive cancer care to the entire population within the catchment area.

#### **CanCon definition of a comprehensive cancer care network**

Based on the European Guide on Quality Improvement in Comprehensive Cancer Control or CanCon definition, a CCCN consists of multiple units\* belonging to different institutions dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation for the benefit of cancer patients and cancer survivors. The objective of a CCCN is to provide comprehensive cancer care to all the people living in a certain geographic area, thus pursuing equality and the improvement of outcomes and quality. Ideally these units interact and have a formal agreement to work together in a programmatic and structured way with common governance, in order to pursue their goals more effectively and efficiently through collective synergies.

\*The word unit is used to designate any component of a CCCN, whether an entire pre-existing institution or a part of an institution. For example, a unit might be an entire cancer centre, an oncology department of a general hospital or a children's hospital, a mammography facility, a pathology laboratory carrying out mutation analysis or a hospice.

### 4.2 Phase 2: survey and interviews

All 28 European Member States are targeted.

The invitation to participate and complete the questionnaire was first sent to JARC partners. In case we did not get any response from our JARC partners we contacted experts involved within the Organisation of European Cancer Institute (OECI) network and national focal points (*The National Focal Points (NFP) are the national experts for the Health Programme in member states and participating countries. NFP representatives are appointed by their national Health Ministries*) (Annex 2\_contact persons).

The email contained the invitational letter stating the purpose of the questionnaire, including the questionnaire itself. In case we did not get any response from all contacted experts we have sent them a reminder four weeks after the beginning. This reminder included an additional phrase asking the respondent if they are the right party to be contacted, and send us the right contact person or forward the mail to the right person in case there were not the right contact person. A second and last reminder followed 3 weeks afterwards in case the first reminder did not have any effect.

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In case the questionnaire was filled unsatisfactory, we replied with specific questions to better understand their responses.

Finally, all respondents received a summary of the results and were asked to confirm or complete/modify the given answers. In case of unsatisfactory information, a telephone call was performed.

Semi-structured interviews were conducted, by telephone, all by the same person. The interviews lasted between 30 and 60 min. It was asked how cancer care was organised in more detail:

- What kind of network model is used? CCCN or hub and spoke or other?
- What is the governance structure of the network? (Is there a formal structure that identifies governing bodies and their respective functions)
- What is the purpose of the network? What is the role of research?
- Is the network evaluated periodically? Do you have indicators to evaluate the network?
- Are there multidisciplinary tumour-specific boards that operate according to agreed treatment protocols across the network?
- Are there cancer care pathways where named coordinators are responsible for making sure that each patient is seamlessly supported along the pathway at the clinical, psychological and administrative level.

The focus was not on CCCN only since in several Member States other type of networks.

**Annex 1:** overview of Member States contacted.

**Annex 2:** contact persons for the Questionnaire.

**Annex 3:** questionnaire "Mapping of Networks of Rare Cancers".

**Annex 4:** results on the Questionnaire.

## 5 Results

Overall, there was a positive response rate of 82% (n=23). With this response rate and the distribution of Member States responded (Figure 1) it was assumed that the answers given are reflecting the situation in the total of the EU (28), but cannot be translated one-to-one. For the Member States that actively participate within the JARC (n=18) the response rate was higher with a rate of 94% (n=17).

### 5.1 Comprehensive cancer care networks in general

In 2017, the final report of the CanCon Joint Action was published.

This report indicated that cancer networks in general do exist in many Member States. In some Member States, a network evolved from or was built around one or two specialized centres (comprehensive cancer centre or similar) that may coordinate research and services throughout a region or throughout the whole of a smaller country. Elsewhere, nationwide cancer networks coexisted with regional networks.

Within the exercise to map the availability of cancer care networks for rare cancers we first update and follow-up the work done by CanCon. To understand if general cancer care networks exists on a national and / or regional level we asked the following questions;

- 1 Is there a national comprehensive cancer care network similar to the CanCon definition provided?
- 2 Are there regional comprehensive cancer care networks similar to the CanCon definition provided?

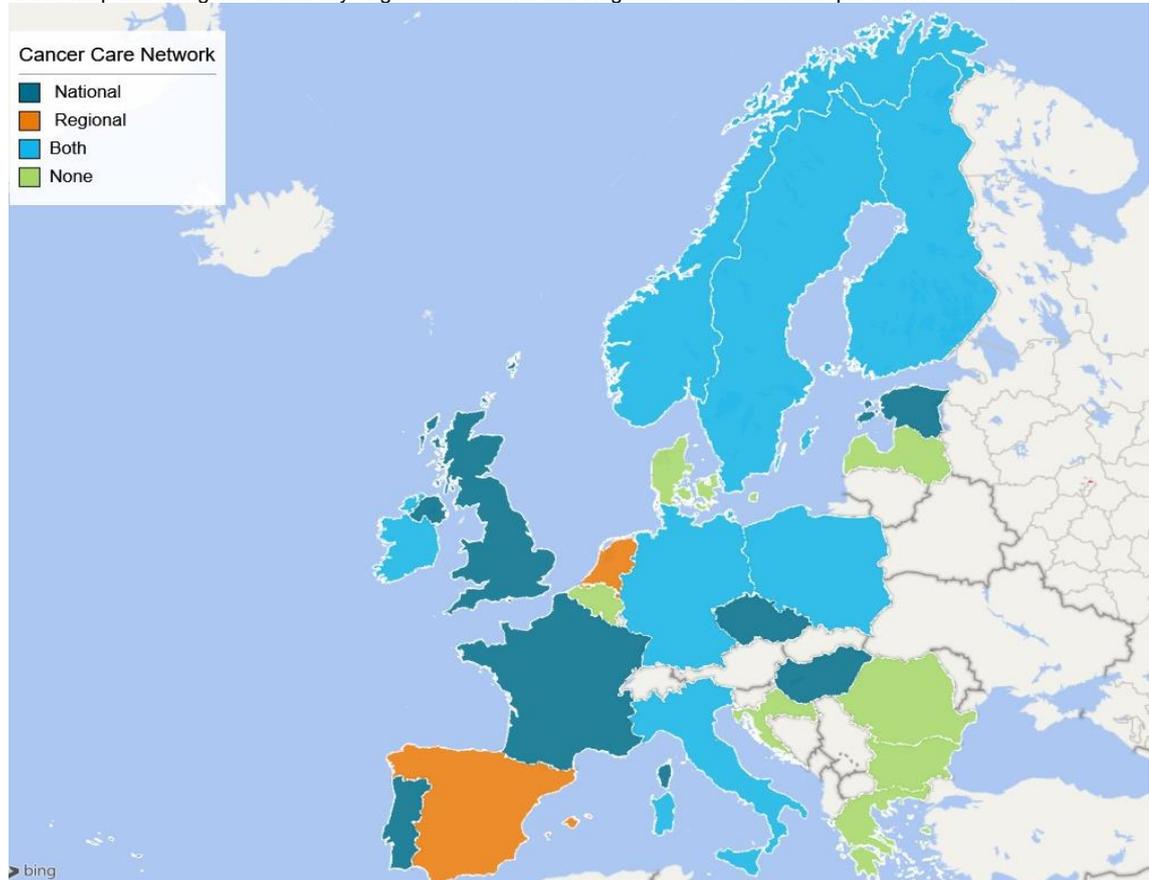
Figure 1 reports the availability of cancer networks in the MS replying to the questionnaire. Out of the 23 respondents:

- 6 (26%) Members States indicated to have cancer networks organised on a national level only and have a coverage of 100% in the country. This accounted France, Portugal, Hungary, UK, Estonia and the Czech Republic;
- 7 (30%) of the Member States do have a National network in coexistence with regional networks. This accounts for Ireland, Germany, Poland, Sweden, Norway, Italy and Finland;
- 2 (9%) Members States indicated to have networks only organised on a regional level. The coverage of these regional networks ranged from 20% to 60% of the Member States. This accounted for Spain, and the Netherlands;
- 8 (35%) Member States indicated that no cancer care networks are available. This accounted for Malta, Greece, Croatia, Latvia, Denmark, Bulgaria, Romania and Belgium.

Figuur 1

Comprehensive cancer care networks in general

JARC map indicating the availability of general National and Regional cancer networks per Member State.



## 5.2 Networks for rare cancers

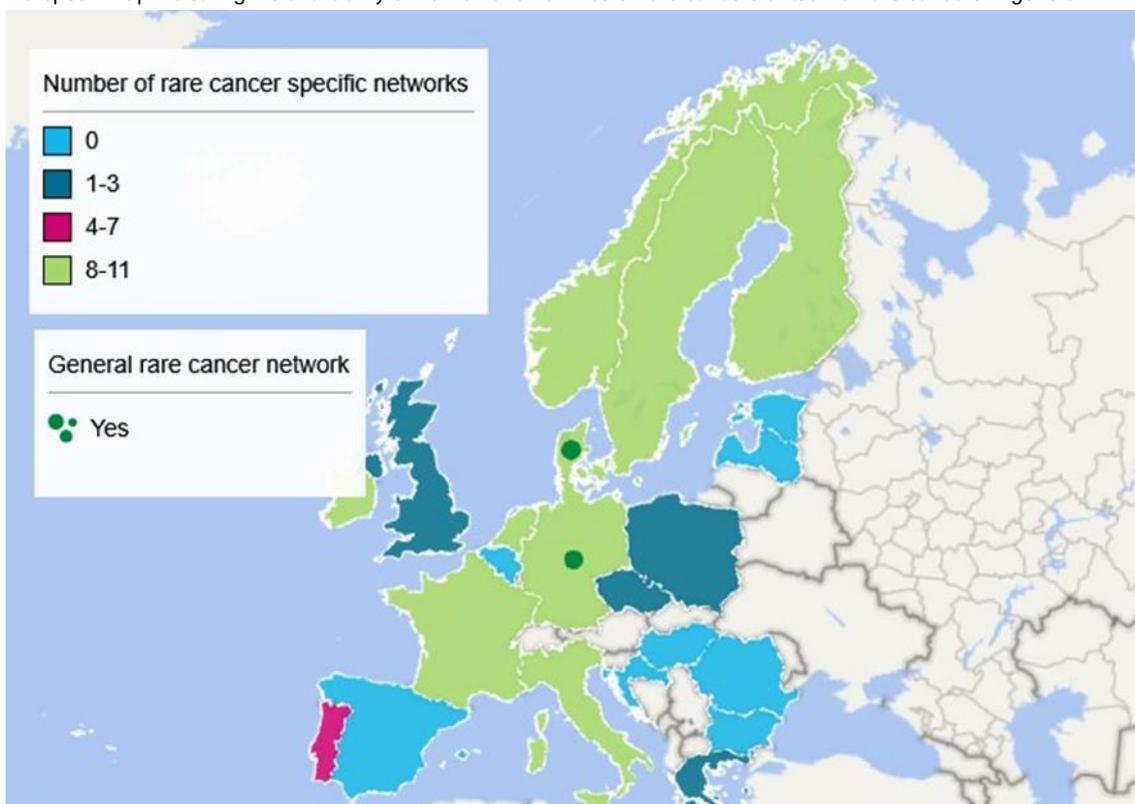
The next step is to map the availability of networks for rare cancers in general and for the specific families of rare cancers.

Currently, the networks for rare cancers are organised in different ways between Member States, but also within a Member State between the different families of rare cancers. Figure 2 reports the availability across MS of networks for rare cancers in general and for specific families of rare cancers.

Figure 2

Networks for rare cancers

European map indicating the availability of networks for families of rare cancers and/or for rare cancers in general



The networks for rare cancers are primarily tumour specific. Only a few Member States have a network for rare cancers in general (N= 2) (Figure 2) please list which are these 2 countries. This accounted for Denmark and Germany.

Denmark has a general national network for rare cancer care, also for different types of rare cancers covering 100% of the country. These networks are responsible for standards of care/clinical guidelines. The networks have online access to information. Further, the board of Health and Welfare defines which rare cancers should be treated where and for most rare cancer types this applies to 2 (sometimes 4) hospitals in the country. Germany indicates to have a national network coexisting with regional networks for rare cancer care.

In 15 Member States cancer care for rare cancers is organised in tumour specific networks (Figure 2). There is a lot of variation between Member States for which families of rare cancers networks exists. Two Member States have a network for one rare cancer family only. This accounted for Czech Republic and Poland, some other Member States do have networks for all 11 families of rare cancers. This accounted for Germany, Italy, Norway, Ireland and Sweden. The tumour specific networks for rare cancers can be organised regional, national or as a combination of both in which national networks coexists with regional networks. Even within a Member State this can vary between families of rare cancers. The coverage of the tumour specific networks varies from 20% to 100%.

This variation between Member States was an item of discussion in the interviews.

Figure 3

Existence of tumour specific rare cancer care networks (National, Regional or Both) by number of Member States in total.



For some families of rare cancers, the existence of networks is less common than others (Figure 3). About half of the responded Member States do have tumour specific networks on sarcomas, neuro-endocrine tumours and haematological tumours. These are the most common tumour specific networks in the EU. Tumour specific networks on thorax and male genital tumours are less common. Respectively 6 and 8 of the responded Member States do have networks for these families of rare cancer.

### 5.3 Unavailability of cancer care networks in general or for (rare) cancers

There should be awareness for the difference in organisation of cancer care in the different Member States throughout the whole of the EU.

Not all Member States have networks built up according to the CanCon definition. This does not always mean that there is no structure or collaboration between hospitals and/or centres of expertise. For example, there are informal structures in which patients follow their clinical pathway through a Member State or region, a more formalized collaboration between hospitals may not directly guaranty the quality of patient care.

Still it can be concluded that in some Member States there is no (informal) structure or organisation concerning cancer care networks.

- 8 (35%) Member States (out of 23 respondents) indicated not to have a general network for cancer care available. For Denmark, Lithuania, Croatia, Bulgaria, Belgium, Romania, Latvia and Greece there is no national or regional network available.

Due to the low number of patients it is difficult to develop expertise in rare cancer care, in this perspective it is found crucial to establish cancer care networks.

- 9 Member States (39%) did not have organised networks for rare cancer care in general or rare cancer specific. This accounted for Spain, Malta, Hungary, Croatia, Estonia, Latvia, Bulgaria, Romania and Belgium.

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Overall result on unavailability of cancer care networks (general (national/regional), rare cancers, rare cancers tumour specific):

- 7 Member States (30%) do not have any kind of cancer care network (general, rare cancers, rare cancers tumour specific). This accounted for Malta, Croatia, Estonia, Latvia, Bulgaria, Belgium and Romania.

## 6 Recommendations

It was recommended in the CanCon Comprehensive cancer control networks guide that CCCNs are built in the Member States to result in a uniformly optimal care be provided as close to home as possible.

In Europe, the ERNs are build up for rare diseases, among these there are 3 ERNs for rare cancers. (ERN-Euracan for rare solid tumours; ERN-PaedCan for paediatrics cancers and ERN-EuroBloodNet for haematological cancers. To integrate the ERNs in the national health care system, it is of importance to define/establish a structure /network in the Member State dedicated to the care of rare cancer patients. Only this way the highest quality of patient care can be achieved for all EU citizens.

Cancer care network for rare cancers are crucial in order to achieve a timely access to appropriate diagnosis and treatment for patients with rare cancers and to support the concentration of resources and patients essential for research and clinical trials. The rare cancer dedicated networks should be inbuilt on the cancer networks when available since rare cancers belong to the world of cancer. Ideally an hub and spoke type of network should be defined in each MS in order to cover all the rare cancers families.

In this report, an overview is given concerning the status of networks in the different Member States. As a result, it was shown that not in every Member State there are networks on (rare) cancers.

Based upon the mapping the recommendations are:

- It is recommended that in every Member State networks of care for rare cancers are established. The organisation of these networks can differ among the Member States.
- The rare cancers network should ensure for rare cancer patients to have access to the expertise available throughout their Member State ensuring the integration of the ERN within the MS.
- It is recommended to establish rare cancer networks covering all rare cancers with a special attention for the tumour types which are less organised in networks according to this mapping (e.g. Rare Thorax tumours and Male Genital Tumours).
- To have a system developed to evaluate these networks it is of importance to develop a set of standards taking into account the existing differences between Member States.

In WP5.2 of our WP5 a set of standards are being developed to evaluate Networks of Cancer Care.

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## Annex

## Annex 1: Overview member states

Country	Participant JARC	Response Questionnaire	Interview
Austria	No	No	
Belgium	Yes	Yes	
Bulgaria	No	Yes	
Croatia	Yes	Yes	
Cyprus	Yes	No	
Czech Republic	Yes	Yes	
Denmark	No	Yes	
Estonia	No	Yes	
Finland	Yes	Yes	
France	Yes	Yes	
Germany	Yes	Yes	
Greece	Yes	Yes	
Hungary	Yes	Yes	Yes
Ireland	Yes	Yes	
Italy	Yes	Yes	
Latvia	No	Yes	
Lithuania	Yes	No	
Luxembourg	No	No	
Malta	Yes	Yes	
Netherlands	Yes	Yes	
Norway	Yes	Yes	
Poland	Yes	Yes	
Portugal	No	Yes	
Romania	Yes	Yes	
Slovakia	No	No	
Slovenia	No	No	
Spain	Yes	Yes	Yes
Sweden	No	Yes	
United Kingdom	Yes	Yes	Yes

## Annex 2: List of contact persons for questionnaire

Country	Contact person	Institute
Austria	Ms Ursula Fronaschütz	National Focal Point Health
Belgium	Marc Van Den Bulcke Jean Benoit Burriion	INSTITUT SCIENTIFIQUE DE SANTE PUBLIQUE/ SCIENSANO Institut Jules Bordet, Brussels, Deputy Director
Bulgaria	Ms Nina Sherbetova Ms Zlatimira Dobreva	National Focal Point National Focal Point
Croatia	Martina Jelinic Mario Sekerija	Croatian National Institute of Public Health Croatian National Institute of Public Health
Cyprus	Myrto Azina-Chronides Ms Elena Makrigiorgi	Ministry of Health, Jarc Participant National Focal Point
Czech Republic	Katerina Kopeckova Petr Cermak	Ministry of Health
Denmark	Mef Christina Nilbert	Danish Cancer Society Research Centre
Estonia	Ms Anneli Sammel Mari-Leen Varendi	National Focal Point Tartu University Hospital, OECI Coordinator
Finland	Enna Degerlund Sakari Karjalainen	Finnish Cancer Society
France	Jeanne-Marie Brechot	Institut National du Cancer
Germany	Kiangenda Tresor Sungu Winkler Peter Hohenberger	
Greece	Maria Gazouli Efimia Boutsikoun Ms Manina Terzidou	University of Athens University of Thesaloniki National Focal Point
Hungary	Dr. Gabriella Fábíán Peter Nagy, Josef Lovey	Department of Oncotherapy, University of Szeged National Oncology Institute, Budapest
Ireland	Paul Walsh Louise Mullen	National cancer registry Board Health service executive
Italy	N. Federici Annalisa Trama	Ministry of Health IEO Milan
Latvia	Ms Inese Andersone Ms Agnija Barona Ms Laura Isajeva	National Focal Point National Focal Point Jarc participant
Lithuania	Ramuna Janavicius Rasa Janciauskiene	Vilnius University Hospital Hospital of Lithuanian University of Health Sciences (LSMU)
Luxembourg	Anne Calteux	National focal point
Malta	Domenic Agius	Malta National Cancer Registry Department for Policy in Health - Health Information and Research
Netherlands	Ms Annemiek Kwast Ms Harriët Blaauwgeers	The Netherlands Comprehensive Cancer Organisation The Netherlands Comprehensive Cancer Organisation
Norway	Bernward Zeller Per Magnus Maehle	Oslo University Hospital, Jarc Participant Oslo University Hospital, OECI coordinator
Poland	Barbara Davriwska	Ministry of Health
Portugal	Ana Carla Correia Marta Pereira Laranja Pontes	National Focal Point Health IPO Porto, OECI contact person IPO Porto, Director
Romania	Razvan Chereches Ms Mariana Postolache Ms Diana Virtaci	University of BB, Jarc Participant National Focal Point National Focal Point
Slovakia	Zuzana Matlonova	National Focal Point
Slovenia	Barbara Medved	National Focal Point
Spain	Josep Maria Boras	University of Barcelona, Jarc participant
Sweden	Ms Anita Janelm Lars Hjorth Eva Gustafsson	National Focal Point PanCare Karolinska, OECI coordinator
United Kingdom	Simon Obers	Cambridge Cancer Center, Jarc Participant

## Annex 3: Questionnaire

### Rationale

The challenges posed by rare cancers combine both the typical problems of rare diseases (such as the limited professional expertise available in the community, or the difficulties in clinical research) and those of cancer, with the need of a timely and correct diagnosis and optimal treatment from the very beginning of the patient's journey. An accurate clinical, pathological and biological assessment of the disease of the individual patient is key to survival and cure, as well as an expert clinical decision provided by a multidisciplinary team. To this end, referral of patients into an effective clinical network is crucial in rare cancers. The goal of the Joint Action on Rare cancers (JARC) is to contribute to improve health outcomes for patients with rare cancers in the EU and to decrease health inequalities across EU countries. Strategically, maximizing chances of European Reference Networks and national networks on rare cancers to be successful is seen as a key factor.

<http://jointactionrarecancers.eu/>.

Work package 5 of the JARC is defining service standards for Comprehensive Cancer Care Networks (CCCN) of rare cancers to ensure best practice and quality of care for patients with a rare cancer across Europe.

In order to promote these standards for CCCN's of rare cancers it is important to know the current state of the existing national and/or regional CCCN's for all 11 families of adult rare cancers in all EU member states.

Families of rare cancer:

Head and neck cancers (cancers of nasal cavity and sinuses, nasopharynx, hypopharynx, larynx, salivary glands, oropharynx, oral cavity and lip, eye, middle ear)

Thoracic rare cancers (tumours of trachea, thymus, malignant mesothelioma)

Male genital and urogenital rare cancers (tumours of testis, penis, renal pelvis, ureter, urethra, and extragonadal germ cell tumours)

Female genital rare cancers (tumours of vulva and vagina, non epithelial tumours of ovary, trophoblastic tumours of the placenta)

Neuroendocrine tumours

Tumours of the endocrine organs (cancers of thyroid, parathyroid, adrenal cortex, pituitary gland)

Central Nervous System tumours (Glial tumours, medulloblastoma, malignant meningioma)

Sarcomas (soft tissue sarcomas, bone sarcomas, gastrointestinal stromal tumours)

Digestive rare cancers (Tumours of small intestine, anal canal, gallbladder and extrahepatic biliary duct)

Rare skin cancers and non-cutaneous melanoma (melanoma of mucosae and of the uvea, adnexal skin carcinomas)

Haematological rare malignancies (acute myeloid leukemia, myeloproliferative neoplasms, myelodysplastic and myeloproliferative neoplasms, histiocytic and dendritic cell neoplasms).

### Definition of a Comprehensive Cancer Care Network (CCCN)

Based on the CANCON definition, a CCCN consists of multiple units\* belonging to different institutions dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation for the benefit of cancer patients and cancer survivors. The objective of a CCCN is to provide comprehensive cancer care to all the people living in a certain geographic area, thus pursuing equality and the improvement of outcomes and quality.

Ideally these units interact and have a formal agreement to work together in a programmatic and structured way with common governance, in order to pursue their goals more effectively and efficiently through collective synergies.

*\*The word unit is used to designate any component of a CCCN, whether an entire pre-existing institution or a part of an institution. For example, a unit might be an entire cancer centre, an oncology department of a general hospital or a children's hospital, a mammography facility, a pathology laboratory carrying out mutation analysis or hospice.*

**1 Name of the Member state**

please, click to fill in

**2 Respondent**

Name: please, click to fill in

function: please, click to fill in.

e-mail address: please, click to fill in

phone number: please, click to fill in

**1 Is there a national comprehensive cancer care network similar to the CANCON definition provided?**

No

Yes, covering please, click to fill in % of the country

If yes, is information about the network online accessible?

No

Yes, url: please, click to fill in the url

Remarks: please, click to fill in

**2 Are there regional comprehensive cancer care networks similar to the CANCON definition provided?**

No

Yes, covering please, click to fill in % of the country

If yes, is information about the network online accessible?

No

Yes, url: please, click to fill in the url

Remarks: please, click to fill in

3 For which of the following (groups) of rare cancers does a national or regional network(s) exist in your country **similar to the CANCON definition provided?**

	National network	Regional network(s)	Information about the network online accessible?	Remarks
<input type="checkbox"/> General for rare cancers	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Sarcoma of the soft tissue, bone, and GIST	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Rare neoplasm of the female genital organs and placentas (tumours of vulva and vagina, non epithelial tumours of ovary, trophoblastic tumours of the placenta)	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Rare neoplasm of the male genital organs, and of the urinary tract (tumours of testis, penis, renal pelvis, ureter, urethra, and extragonadal germ cell tumours)	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Neuroendocrine tumours (NET)	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Rare neoplasm if the digestive tract (Tumours of small intestine, anal canal, gallbladder and extrahepatic biliary duc	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in

	National network	Regional network(s)	Information about the network online accessible?	Remarks
<input type="checkbox"/> Rare neoplasm of endocrine organs (cancers of thyroid, parathyroid, adrenal cortex, pituitary gland)	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Rare neoplasm of the head and neck (cancers of nasal cavity and sinuses, nasopharynx, hypopharynx, larynx, salivary glands, oropharynx, oral cavity and lip, eye, middle ear)	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Rare neoplasm of the thorax: Thymoma, mediastinum and pleura	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Rare neoplasm of the skin and eye melanoma (Rare Skin/Eye melanoma)	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Central Nervous System tumours (Glial tumours, medulloblastoma, malignant meningioma)	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in
<input type="checkbox"/> Haematological rare malignancies (acute myeloid leukemia, myeloproliferative neoplasms, myelodysplastic and myeloproliferative neoplasms, histiocytic and dendritic cell neoplasms)	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	click to fill in

	National network	Regional network(s)	Information about the network online accessible?	Remarks
<input type="checkbox"/> Other	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, covering click to fill in % of the country	<input type="radio"/> No <input type="radio"/> Yes, url click to fill in the url	
<input type="checkbox"/> None				

## Annex 3: Results per Member State

Member State	Network (general) cancer care		Network for <u>rare</u> cancers			Remarks
	National	Regional	National in General	Regional in General	Tumour specific* *(N) = national; (R) = regional	
Spain	X	✓ covering 20% of the country	X	X	X	<ul style="list-style-type: none"> <li>- Regional networks in specific territories that cover a high percentage (more than 70%) of care in Catalonia, and also in the North, South and NorthEast part of Barcelona</li> <li>- In other regions of Spain with lower percentage of population covered</li> <li>- Total coverage about 20% of the country.</li> <li>- There are centres of expertise for sarcomas and paediatric cancers, designated by NHS. These hospitals provide complex cancer care for these tumour types, but not within a network.</li> <li>- There is referral between hospitals for specific treatment, this is informally organised (pragmatic).</li> </ul> <p>The health care system is very strong decentralised in Spain, 17 regions and they have all their own organisation (content is the same).</p>
France	✓	X	X	X	Sarcomas (N) Gynaecology (N) Urology (N) NET (N) Endocrine (N) Head & Neck (N) Thorax (N) Skin / Eye Melanoma (N) CNS (N)	There are national CCCN organised by families of rare cancers
Malta	X	X	X	X	X	<p>There are no national or regional CCCNs in which Malta is involved.</p> <p>Malta is too small to have a CCCN either at the national or regional level.</p> <p>The treatment abroad services (National Highly Specialized Overseas Referrals Programme; Bilateral Agreement with the United Kingdom (since 1975)) can be viewed to function as a CCCN for the management of our patients with several forms of rare cancers.</p> <p>Patients that are referred for and approved to access this service are sent to applicable centres of expertise in the UK.</p> <p>Patients are also followed up by local specialists in collaboration with their counterparts in these specialised centres and there are also a number of visiting consultants who come to Malta to conduct planned follow-up out-patients sessions and surgical theatre lists.</p>

Member State	Network (general) cancer care		Network for <u>rare</u> cancers			Remarks
	National	Regional	National in General	Regional in General	Tumour specific* *(N) = national; (R) = regional	
Finland	✓ covering 100% of the country	✓ covering 80% of the country	X	X	Gynaecology (N) NET (N) Digestive tract (N) Endocrine (N) Head & Neck (N) Skin / Eye Melanoma (N) CNS (N) Haematology (N)	No general network for rare cancers, but items are covered under the Finnish Oncology Society. For the rare tumour types without a network, there are non-formal specialised groups, e.g. sarcomas (on Scandinavian level).  There are regional cancer centres in over 15 hospitals and 2 comprehensive cancer centres (South and West)
Hungary	✓ covering 80 - 90% of the country	X	X	X	X	CCCN (honcology.net) Structure CCCN: 1 national Onco centre and 4 regional centres, this includes 3 univers. and one big. 13 (bigger) hospitals but do not all have the complete equipment like radiotherapy.  Other hospitals, who are not included in the CCCN should not provide care to oncology patients but still some do (10-20%).  There are rules how patients should be referred from a national level. The NHS provides these rules.  There is no network for rare cancers in Hungary. There is a working group on NET but it is not known if there is a formal agreement for this collaboration.
Czech Republic	✓ covering 95%	X	X	X	Haematology (both N and R)	www.onconet.cz Comprehensive Cancer Centres (CCC) are healthcare facilities – or association of healthcare facilities – which fulfil the criteria of providing healthcare to cancer patients, as declared by the Czech Society for Oncology.  The Czech network of CCC was established already in 2006. And a list of centres for highly specialised cancer care is defined by the government.
Germany	✓ covering 80% of the country	✓	✓	✓	Sarcomas (N)(R) Gynaecology (N)(R) Urology (N)(R) NET (N)(R) Digestive tract (N)(R) Endocrine (N)(R) Head & Neck (N)(R) Thorax (N)(R) Skin / Eye Melanoma (N)(R) CNS (N)(R) Haematology (N)(R)	<a href="http://www.ccc-netzwerk.de/">http://www.ccc-netzwerk.de/</a> <a href="http://www.ccc-netzwerk.de/patienteninformation/links.html">http://www.ccc-netzwerk.de/patienteninformation/links.html</a>

Member State	Network (general) cancer care		Network for <u>rare</u> cancers				Remarks
	National	Regional	National in General	Regional in General	Tumour specific* *(N) = national; (R) = regional		
Italy	✓	✓	✗	✗	Sarcomas (N)(R) Gynaecology (N)(R) Urology (N)(R) NET (N)(R) Digestive tract (N)(R) Endocrine (N)(R) Head & Neck (N)(R) Thorax (N)(R) Skin / Eye Melanoma (N)(R) CNS (N)(R) Haematology (N)(R) Paediatrics (N)(R)	Professional networks (which do not fit with the definition of CanCon) were available in Italy for paediatric cancers (led by the Italian association of pediatric hemato-oncology - AIEOP); for haematological tumours (GIMEMA) and for most rare solid cancers (rare cancer network).  A National network for rare cancers (RCNN) is under construction: according to the European concepts it is articulated in three sub-network for solid tumours (all families), paediatric cancers and onco-haematology. This national network should be coordinated with the regional cancer networks. About the models: the regional cancers networks refer to the CCCN model.	
The Netherlands	✗	✓	✗	✗	Sarcomas (N)(R) Gynaecology (N)(R) Urology (R) NET (R) Digestive tract (N)(R) Endocrine (R) Head & Neck (N)(R) CNS (N)(R) Haematology (N)(R) Paediatrics (N)	In the Netherlands there is no national network for cancer care. In the regions there are general networks for cancer. There is also no national network for rare cancers. For most rare cancer tumour types there are networks, however not all completely formalised.	
Greece	✗	✗	✗	✗	Sarcomas (N)(R) NET (N)(R)		
Croatia	✗	✗	✗	✗	✗		
Poland	✓ covering 100% of the country.	✓	✗	✗	✗	Www.puo.pl/dla-pacjentow/osrodki-onkologiczne  There are 16 oncology centres in Poland that play the role of regional and national centres at the same time. In these centres, all cancers are treated, including rare neoplasms and also there are in our country oncological departments in General hospitals and Children's hospitals and Clinical hospitals based on the Medical Academy, which guarantee comprehensive cancer care.	
Estonia	✓	✗	✗	✗	✗	Yes, we can say that a general oncology network is existing between 3 hospitals that offer diagnostics and treatment in oncology. This is not exactly following the definition of Cancon for a CCCN.  There is cooperation between the hospitals and specially for example head and neck cancers. Some discussion has been done to formalize this, but this is still in planning phase.	

Member State	Network (general) cancer care		Network for <u>rare</u> cancers			Remarks
	National	Regional	National in General	Regional in General	Tumour specific* *(N) = national; (R) = regional	
Portugal	✓ covering 100% of the country	X	X	X	Sarcomas (N) Urology (N) Digestive tract (N) Skin / Eye Melanoma (N) Paediatrics (N)	
Norway	✓	✓	X	X	Sarcomas (N) Gynaecology (N) NET (R) Digestive tract (N) Endocrine (N) Head & Neck (N) Thorax (N) Skin / Eye Melanoma (N) CNS (N) Haematology (N) Paediatrics (N)	There are for all tumour groups national tumour boards responsible for national guidelines, but these groups do not fulfil all criteria for a CCCN.  There are regional advisory cancer boards. Their objectives include allocation of cancer surgery within the region; i.e. between the university hospital and other hospitals
Latvia	X	X	X	X	X	
Denmark	X	X	✓ covering 100% of the country.	X	Sarcomas (N) Gynaecology (N) Urology (N) NET (N) Digestive tract (N) Endocrine (N) Head & Neck (N) Skin / Eye Melanoma (N) CNS (N) Haematology (N)	National network general for rare cancers, covering 100% of the country  Remark: Refers to the networks described and to the national definition of which cancer types are treated where
Bulgaria	X	X	X	X	X	No specifically designated cancer care networks in Bulgaria. Care for patients with cancer is provided in hospitals (incl. specialized hospitals for oncological diseases and multi profiled hospitals) and complex oncological centres. Complex care is required for all cancer patients that involve diagnosis, treatment (including determination of treatment plan for patients with malignancies, radiotherapy, surgery and radiosurgery, systemic drug treatment, staging and evaluation of therapeutic response, monitoring the therapeutic response in patients during home treatment, outpatient monitoring / dispensarisation in malignant diseases), and palliative care for patients with oncological diseases. Different phases of treatment could be performed in different medical awards and centres according to their competences and possibilities as well as patient choice.

Member State	Network (general) cancer care		Network for <u>rare</u> cancers			Remarks
	National	Regional	National in general	Regional in general	Tumour specific* *(N) = national; (R) = regional	
						In Bulgaria, there is no specified networks for tumour specific rare tumour types. Care for patients with cancers is provided by medical centres and medical specialists in accordance with their competences.
Ireland	✓ covering 100% of the country	X	X		Sarcomas (R) Gynaecology (R) Urology (R) NET (N) Digestive tract (R) Endocrine (R) Head & Neck (R) Thorax (R) Skin / Eye Melanoma (R) CNS (N) Haematology (R)	
UK England	✓	X	X	✓	X	There is no formal cancer network; not cancer specific network that provide patient care. .... Previous: The 28 formal (regional) networks provide guidelines / pathways of care / clinical development / innovation. All UK hospitals are covered by these 28 networks.
UK Wales	✓	X	X	✓	X	There is no secretariat. There is no website. It is not visible. The cooperation still exist. Also, development on the specific activities rare cancers were there, but not network wise per definition network wise but is evolving. It is difficult to state when it is officially a network. Scotland: 3 clinical networks for cancer and 3 for specific rare cancers (sarcomas, haematology, paediatrics), comparable to the alliances Norther Ireland & Wales 1 network for all cancers So, there are 3 national networks and work together in the UK
UK Scotland	✓	X	X	✓	Sarcomas (N) Haematology (N) Paediatrics (N)	
Romania	X	X	X	X	X	
Sweden	✓	✓	X	X	Sarcomas (N) Gynaecology (N) Urology (N) NET (N) Digestive tract (N) Endocrine (N) Head & Neck (N) Thorax (N) Skin / Eye Melanoma (N) CNS (N) Haematology (N)	There is no national comprehensive centre in the way you define it. We have national networks for all cancers. The network consists of professionals and they write national clinical guidelines for the diagnoses. I work for regional cancer centres in collaboration which is an organisation of all regional cancer centres (including Stockholm). We support the county councils with cancer registers, national guidelines, and make recommendations for centralization of certain procedures or diagnoses with few numbers of patients. The county councils are responsible for the actual care of cancer patients. They make agreements and collaborate with each other for some of the rare cancer diagnoses. We have national networks for many of the rare cancers. The groups are responsible for cancer care guidelines, quality registers and research. Each county council (we have 21 in Sweden) is responsible for the care and they have different agreements with other county councils for care of rare cancer diagnoses. See also our website: <a href="https://cancercentrum.se/samverkan/">https://cancercentrum.se/samverkan/</a> (all information in Swedish.)
Belgium	X	X	X	X	X	

