RARECARENet country report

Belgium

Draft for review

4th July 2016

EUROPEAN CANCER PATIENT COALITION

Belgian Cancer Registry

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1. Introduction

In 2011 the RARECARE (surveillance of rare cancers in Europe) project proposed a new definition for rare cancers and quantified the burden of rare cancers in Europe. RARECARE showed that rare cancers pose an important challenge in Europe. They are thought to represent nearly one quarter of all new diagnoses of cancer in Europe (22%) and have lower survival rates than common cancers. Thus obtaining reliable estimates of the number and type of rare cancers, and identifying ways to improve the quality of care for patients should be recognised as a public health priority.[1]

A second project, **Information Network on Rare Cancers (RARECARENet)** was established in 2012 with the aim **to build an information network that may provide comprehensive information on rare cancers to the community at large.**

The RARECARENet project had 3 main components:

- **European and country-specific epidemiological indicators** were estimated on the basis of population-based cancer registries (94 cancer registries from 24 European countries corresponding to 46% of the population of the European Union).
- A '**Pilot Study on hospital volume**' examined the extent of rare cancer treatment centralisation, and looked at the association between hospital volume and outcomes for two types of rare cancers – sarcomas and head and neck cancers.
- A wide consensus process together with a '**High resolution study on Centres of Expertise for rare cancers'** identified quality criteria for centres of expertise in the management of rare cancers.

(For a fuller description of the RARECARENet project, see **Appendix 1***).*

In addition, multi-stakeholder meetings were organised in four countries (Belgium, Bulgaria, Slovenia, and Ireland) to discuss the emerging public health issue of rare cancers in each country. These meetings allowed the RARECARENet team to present to participating local expert country-specific findings from their epidemiological studies, and discuss how the management of rare cancers may be improved locally for the benefit of patients.

The purpose of this report is to summarise the main discussions and recommendations from the RARECARENet meeting that took place in Belgium on the 16th April 2015. The meeting gathered European and local experts on rare cancers (epidemiologists, oncologists, surgeons, and pathologists), representatives from The European Organisation for Research and Treatment of Cancer (EORTC) and the Organisation of European Cancer Institutes (OECI), cancer registry leads, patient organisations and representatives of the Ministries of Public Health. The meeting was co-hosted by the European Cancer Patients Coalition and the Belgian Cancer Registry. (*The meeting agenda and the list of participants is provided in* **Appendix 2***).*

Discussions focused on four key priorities which correspond to the focus of the RARECARENet project:

- Describing the epidemiology of rare cancers in Belgium
- Discussing the most appropriate quality indicators for centres of expertise for specific rare cancers
- Discussing the availability of centres of treatment for rare cancers in Belgium
- Identifying existing challenges in the management of rare cancers in Belgium.

2. The epidemiology of rare cancers in Belgium

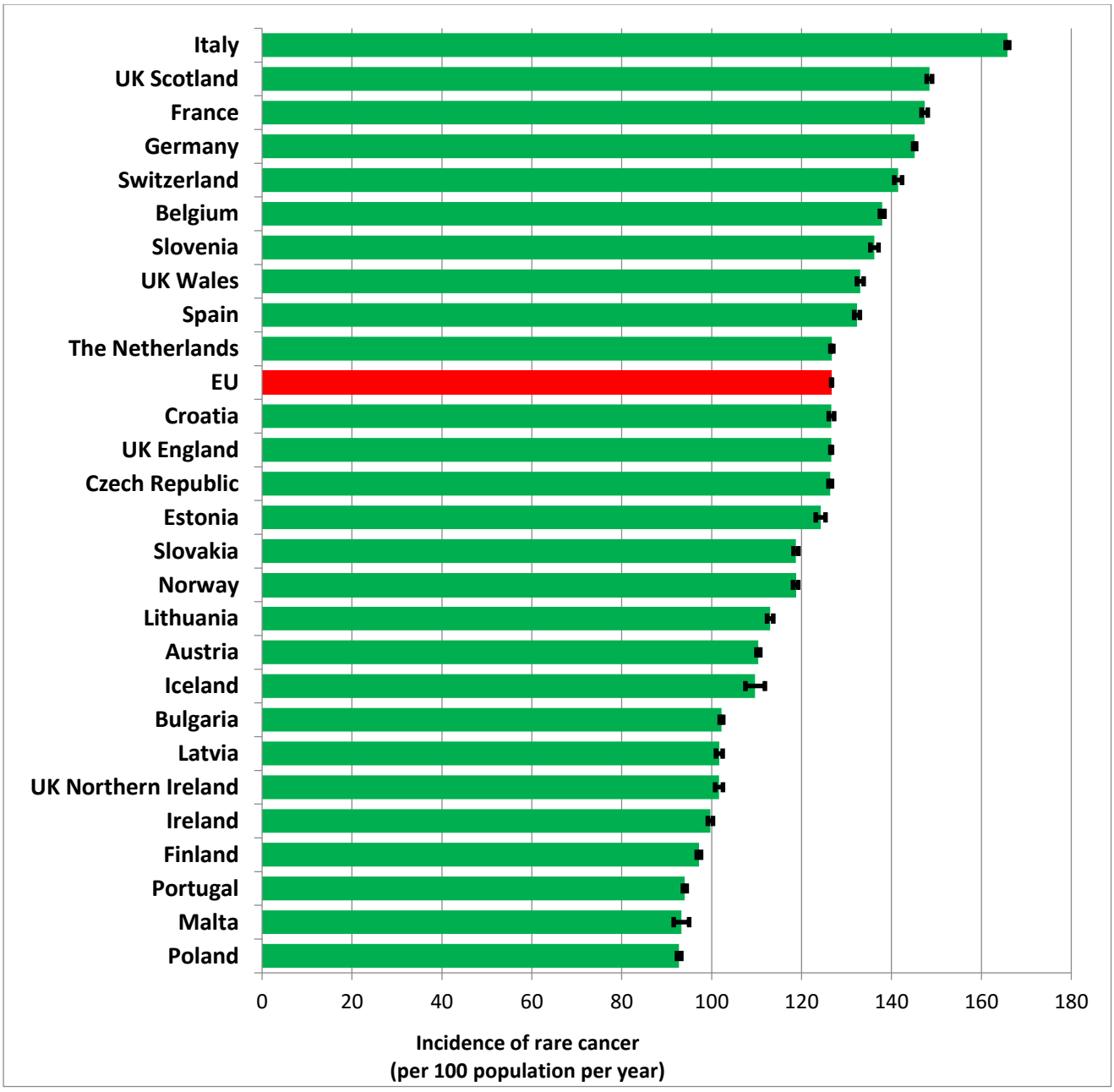
Rare cancers account for 23% of the total cancer diagnoses in Belgium

Belgium has approximately 14,000 new cases of rare cancers per year, accounting for 23% of the total cancer diagnoses. This similar to the average across Europe (22%). The small numbers of cancers involved will have important implications for planning and management of these diseases.

The incidence of rare cancers in Belgium, grouped by different crude incidence cut-off rates, can be seen in **Appendix 3**.

Incidence of rare cancers in Belgium is among the highest across Europe, as demonstrated in **Figure 1**.

Figure 1 - Incidence of rare cancers across Europe



Belgium has a relatively high survival rate for rare cancers, however survival rates are still lower than for common cancers

Using the RARECARENet database, survival analysis for rare cancers was performed per country for the period of diagnosis 2000-2007. Overall the survival of all rare cancers ranged between 30-60% and Belgium has a relatively high survival for rare cancers. Despite this, there is a similar trend between all countries, that survival rates for rare cancers are lower than those for common cancers.

3. Quality indicators for centres of expertise for rare cancers

Criteria for centres of expertise in the management of rare cancers

As mentioned previously, one of the main outputs of the RARECARENet project was the specification of general quality criteria for centres of expertise in the management of rare cancers. These criteria were then used to develop specific quality indicators for different cancer types (see **Appendix 4**). The general quality indicators were developed at a European level, based on a consensus approach, utilising both evidence from previous experience at the European level (the European Commission committee of experts on rare diseases) and country level.

According to the general quality criteria, centres of expertise should:

1. Ensure appropriate **clinical management** according to evidence-based guidelines and based on **a patient-centered multidisciplinary approach**
2. Develop/support **patient pathways** nationally and across borders
3. Develop **clinical guidelines** and **good service delivery guidelines**
4. Guarantee a learning environment by **promoting training** and continuing education activities
5. Foster clinical, translational and epidemiological **research for rare cancers**
6. **Empower patients** by providing information adapted to their specific needs, culture and ethnic group
7. Possess an **e-health platform** to process and share information, biomedical images or clinical samples supported by enough human and structural resources as well as equipment
8. Have a transparent quality assurance system including **monitoring and evaluation** of the service provided
9. Consistently **report the volume** of patients treated for rare cancers.

These general criteria for centres of expertise aided the development of **specific quality criteria for the clinical management of rare cancers**. Key aspects of clinical management relevant to all cancers are presented in **Table 1**. Specific indicators relevant to three rare cancers (sarcomas, head and neck cancers, and testicular cancers) were developed. During the meeting the criteria for sarcomas and testicular cancer were discussed, and the results for sarcomas and testicular cancers are presented in **Appendix 4**.

Table 1: Main areas of the clinical management from which rare cancer specific quality criteria for centres of expertise have been proposed.

Critical areas	**Why is this important for rare cancers?**
Appropriate and timely diagnosis and staging procedures	Due to the rarity of these cancers, many doctors are unable to make a prompt diagnosis, and pathologists may not have enough experience to identify the cancer. A high level of experience is also necessary for performing all correct staging procedures. The lack of experience due to the rarity of these tumours leads to incorrect or delayed diagnosis and poor staging procedures. This may be compounded by the lack of clear referral pathways, since centres dedicated to rare cancers may not exist or may not be known to general practitioners and other healthcare professionals.
Quality of care	Lack of knowledge and clinical expertise among health care professionals treating rare cancers may result in suboptimal care.[1] Because of the rarity, it is difficult to perform clinical trials and therefore develop evidence-based clinical guidelines. When available, the adherence to clinical guidelines is critical to ensure patients receive the most appropriate, evidence-based care. Independent of clinical guideline availability, it is important to have clinical management agreed upon by a multidisciplinary team, as it ensures a higher quality of care for rare cancer patients.
Quality of pathological report after surgery	Pathological reports are essential for planning appropriate treatment. Ideally, pathology reports should contain a full set of the core data defined by the relevant scientific society guidelines, however a complete set of these standardized data are often missing in reports, challenging the definition of the appropriate treatment plans.
Quality surgery and radiotherapy	Due to the rarity of these cancers, it is difficult to find experienced surgeons and/or radiotherapists. Poor quality surgery and radiotherapy can lead to re-operation or recurrences, which are avoidable and may have a high impact on the quality of life for patients.
Availability of formalised multidisciplinary decision-making	Multidisciplinary teams are important for the management of rare cancers,[2] as they allow health care professionals from a range of disciplines to work together to provide a comprehensive treatment plan for patients. This is of particular importance for rare cancers due to the limited availability of scientific evidence. Additionally, multidisciplinary teams in high volume centres have been associated with better outcomes, shorter delays between diagnosis and treatment and a greater availability and range of therapeutic options.[2]
Participation in clinical and translational research	Given the small number of new rare cancer cases each year, it is often difficult to obtain a strong evidence base on which to build clinical management guidelines and protocols. Therefore, centres of expertise should network with other centres across Europe to participate in clinical trials, with the aim to improve accuracy and standardisation of diagnosis and treatment for rare cancers. [1]

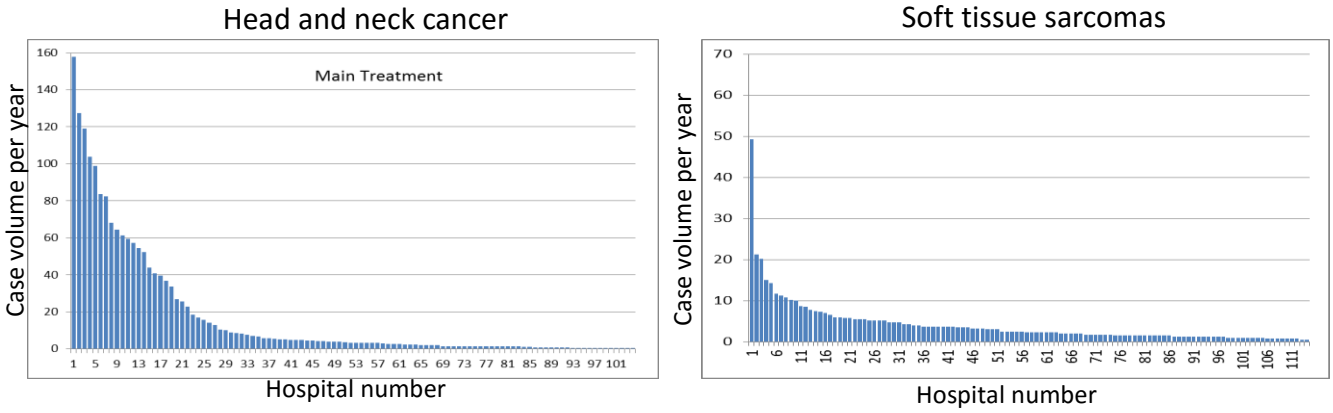
4. Treatment centres for rare cancers in Belgium

Centralisation of care is viewed as critical for the management of rare cancers to allow specialists and health professionals to diagnose and treat a larger number of these rare cases. Mr Benoit Mores, advisor within the Ministry of Health and Social Affairs, discussed the future goal to promote centres of expertise for rare cancer diagnosis and treatment. Ensuring high quality care through centralisation of care is also proposed in legislation such as the National Cancer Plan[3] and the Belgian Rare Diseases Plan.[4]

The Belgian Health Care Knowledge Centre (KCE) was commissioned by the Ministry of Health and Social Affairs to define treatment pathways and professional capacity required to manage rare cancers, and propose scenarios for the organisation of care for rare cancers in Belgium. The study showed oncology treatment occurring across 106 hospitals in Belgium, and a rare cancer patient can be treated at any of these centres. As the management of rare cancers could occur in any hospital, every rare cancer patient may not be treated by a highly experienced multidisciplinary team and receive the best quality care.

However, the division of healthcare between the national and federal levels will challenge the drive towards centralisation. To work within the existing health care system, the 'shared care' model of centralisation has been suggested by the KCE, whereby treatment is planned in Reference Centres, but also carried out in peripheral centres convenient to the patient. This will be enhanced by the access to specialised multidisciplinary oncological consults (MOC/COM) to ensure optimal management, and for very rare or complex cases 'super MOC/COMs' will enable discussion between experts across national and international Reference Centres.

Figure 2 -Hospital volumes for the main treatment of head and neck cancers and soft tissue sarcomas from the RARECARENet Pilot Study. Hospitals were ranked by decreasing volume after blind coding.



Rare cancers differ in their degree of centralisation in Belgium, as is illustrated in **Figure 2.** But in both cases, the level of centralisation is low. For head and neck cancers radiotherapy treatment is often centralised to specific centres based on availability of facilities. However, for both types of cancer, In Belgium, there are a large number of patients seen in hospitals seeing less than 20 cases per year.

Results from the pilot study in Belgium, which assessed the relationship between hospital volume and survival, found that patients with locally advanced head and neck cancer treated in low volume hospitals had almost a double risk of death compared with those treated in high volume hospitals.

The EU Joint Action "Comprehensive Cancer Control" (CanCon) was established to reduce cancer mortality and improve survival, through identifying quality standards and guidelines for care, improving quality of life for patients and facilitating cooperation between member countries. Following the establishment of CanCon, the European Cancer Patients Coalition (ECPC) conducted a survey of 23 CanCon EU Member-State representatives to further understand the referral for rare cancers in each country represented in CanCon and whether specific treatment centres had been identified.

The survey identified that Belgium has a legal framework for oncology care program which sets out a list of criteria to be fulfilled by a hospital in order to qualify for recognition as an oncology care centre. These oncology care hospitals are identified according to general criteria for oncology[5] and a list of the hospitals is available, however there is no identification of specialised rare cancer centres.

Specialised criteria for a number of rare cancers were proposed by the Belgian Health Care Knowledge Centre, with recommendations for the organisation of the healthcare system.[6] Implementation of these recommendations is currently in preparation.

5. Challenges in the clinical management of rare cancers in Belgium

General challenges in the management of rare cancers in Belgium

The management of rare cancers generally poses challenges, due to their small numbers and lack of available specialists. Some of the most important challenges raised in Belgium for the management of rare cancers confirm the relevance of the quality criteria chosen and the importance of centralised care. They included:

- **Delays in diagnosis** could be due to limited experience from pathologists, limited access to second opinions, lack of centralisation and the complexity associated with diagnosing certain rare cancers. Due to this, tissue samples are frequently sent abroad for diagnosis.
- **Low volume centres may not be able to provide the highest quality surgery and radiotherapy**
- **Low levels of treatment centralisation are a** challenge for the provision of continuous, high quality care for every patient
- **Mixed support for centralisation from smaller peripheral healthcare centres**
- **Improve and standardise electronic patient records** to facilitate the transfer of information between treatment centres
- **At this moment, there seems to exist a low level of involvement in the translation of clinical research** into day-to-day management of rare cancers
- **Division of the health care capacity into the national and federal levels is a challenge.**

Details on Sarcomas from the High Resolution Study can be found in **Appendix 4.**

6. Recommendations for the future

Key recommendations for the improved management of rare cancers have been developed for Belgium. These are summarised for all rare cancers below:

Overall recommendations for rare cancers

1. Improve the standardisation of care for rare cancers to reduce treatment inequalities across centres and improve patient quality of care:

    - **Ensure that primary treatment is planned at a multidisciplinary meeting** to improve collaboration among different specialists, quality of pathology reporting and timely start to treatment
    - **Implement national and international pathways for rare cancers, setting minimum standards of quality for services**
    - **Standardise pathology reporting after surgery**, with a common set of information to be collected for every patient
    - **Define a pathway for second opinion for diagnosis/treatment of extra rare cancers** and ensure that second opinions are properly reimbursed.

2. Empower patients to take a stronger role in their care:

    - **Organise meetings with patients and patient associations** to discuss the importance of centralisation for quality of care and better outcomes
    - **Improve communication between clinical experts and patient representatives** to create a stronger local advocacy base for the better management of rare cancers.

3. Increase the research base and collaboration in rare cancer care:

    - **Use a population-based cancer registry** as one of the data source to identify and monitor centres of expertise
    - **Involve scientific societies in the discussion on quality indicators**
    - **Publish scientific papers to support the importance of centralisation** for rare cancer care in Belgium
    - **Utilise European Reference Networks** to enable cross-border collaboration for clinical management, second opinions and clinical research
    - **Include rare cancers as a priority within the cancer control strategy.**

Appendices

Appendix 1: About the RARECARENet Project

RARECARE (Surveillance of rare cancers in Europe) data provided a first understanding of the burden posed by rare cancers. RARECARENet project aims at create an information network to provide and disseminate comprehensive information on rare cancers to oncologists, general practitioners, researchers, health authorities, patients and the general public. Additionally, RARECARENet aim to further develop a comprehensive list of patient associations which are dedicated to rare cancers. These objectives are carried out with the eventual aim to improve the timeliness and accuracy of diagnosis, facilitate access to high quality treatment for patients with rare cancers, to identify centres of expertise for rare cancers in Europe and standardise practice across member states. The data facilitating these improvements has been found through the following studies:

RARECARENet EUROCARE-5 is an adult database which was created to update the epidemiological indicators for rare cancers. It covers 94 cancer registries (89 of which were in RARECARE) in 24 countries (19 of which participate in RARECARE). The database covers 48% of the population of the countries participating in RARECARENet, and 46% of the population in the European Union (excluding Norway, Switzerland and Iceland). This database was used to calculate incidence, prevalence and survival of rare cancers.

RARECARENet 'Pilot Study on hospital volume' investigated the extent of centralisation of rare cancer treatment in selected European countries on the basis of population based cancer registries with national coverage. Countries with national coverage were Belgium, Bulgaria, Finland, Navarra (a region of Spain), Ireland, Slovenia and the Netherlands. Objectives of this study were to estimate indicators of the degree of centralisation, map the hospitals where rare cancers are most frequently treated, and analysing the association between hospital volume and outcome for select rare cancers.

RARECARENet 'High resolution study on Centres of Expertise for rare cancers' looked to identify quality criteria for centres of expertise for the management of rare cancers. Through discussion with clinicians, experts, epidemiologists, patient representatives, and cancer registries, general criteria for centres of expertise and specific indicators for selected rare cancers (sarcomas, testicular and head and neck tumours) were identified. The cancer-specific indicators were analysed to test their appropriateness on a retrospective analysis of studying hospital patient files and pathology reports in selected participating cancer registries from Belgium, Bulgaria, Finland, Ireland, Italy, Slovenia and the Netherlands.

RARECARENet 'Information for patients and professionals' was created to provide meaningful information to the community at large. A list of clinical guidelines on rare cancers was developed based on already available information and on new information collected and created in collaboration with State-of-the-Art Oncology in Europe (START), the European Society for Medical Oncology (ESMO) and epidemiological data from the project, Surveillance of Rare Cancers in Europe. The RARECARENet website also provides a list of information materials on rare cancers for patients on the diagnosis, treatment and follow-up of any type of rare cancer. The information has been collected from rare cancer patient organisations participating in the project, more information can be found on the RARECARENet website - http://www.rarecarenet.eu/rarecarenet/index.php/information-on-rare-cancers

Finally, a list of 144 rare cancer patient organisations in Europe was created with the aim to build a network to support patients with rare cancers. The list is available on the RARECARENet website - http://www.rarecarenet.eu/rarecarenet/index.php/patient-organisations

Appendix 2: Agenda for the Dublin meeting on Rare Cancers

Meeting Agenda

RARECAREnet Meeting on Results of the High Resolution Studies in Belgium and on Quality of Care for Rare Cancers

April 16th, 2015, 13:00–18:00

Time	Topic	Responsibility
13.00-15.00	**Welcome, introduction round, program and aim of the meeting**	Dr. Gemma Gatta, Ms. Kalliopi Christoforidi, RARECAREnet staff
	RARECAREnet project overview	Dr. Gemma Gatta, RARECAREnet staff
	Presentations on the situation in the country on rare cancers	
	'Organisation of care for adults with a rare or complex cancer' Belgian Health Care Knowledge Centre Report 219	Mrs. Sabine Stordeur, Belgian Health Care Knowledge Centre
	Point of view of the Belgian Ministry of Health.	Mr. Benoit Mores, Advisor Ministry of Health and Social Affairs
	Point of view of the Flemish Ministry for Welfare, Public Health and Family	Mr. Geert Peuskens, Agency for Care and Health (Agentschap Zorg en Gezondheid), Flemish Ministry for Welfare, Public Health and Family
	'Set up of a pathology reference network', Belgian Health Care Knowledge Centre Report, 219	Dr. Kristof Cokelaere, Belgian Society of Pathology, College of Oncology
15.00-15.30	**Coffee break**	
15.30-17.00	**Presentation of quality criteria**	Dr. Annalisa Trama, RARECAREnet staff
	Results of the RARECAREnet studies on the criteria (results for Belgium)	Dr. Liesbet Van Eycken, Belgian Cancer Registry
	Discussion on the quality criteria proposed	Prof. Karin Haustermans, Chair of the Scientific Council of the Belgian Cancer Registry
	Results of the volume analyses of the country	Dr. Riccardo Capocaccia, RARECAREnet staff
	Identification of treatment centres by ECPC	Ms. Kalliopi Christoforidi, RARECAREnet staff (ECPC)
17.00-18.00	**Discussion on the level of centralization and hospital volume for the specific country**	RARECAREnet staff and Prof. Karin Haustermans, introducing the session with a speech on criteria
	Possible conclusions, way forward and discussion on how to identify the centres and what the country is intended to do?	RARECAREnet staff and Prof. Karin Haustermans, Chair
18.00	**End, Close of the Day**	

List of participants:

Name	Position	Institution
Dr Didier Vander Steichel	Medical and scientific director	Fondation contre le Cancer
Erwin Lauwers, PhD	Project manager biomedical research	Kom op tegen kanker
Alessandro Gronchi MD	Chair Sarcoma Service - Department of Surgery	Fondazione IRCCS Istituto Nazionale dei Tumori Milan - Italy
Sabine Stordeur, PhD	Senior Expert in Clinical and Health Services Research	Belgian Health Care Knowledge Centre
Professor Marc Hamoir	Chairman of the Executive Board. King Albert II Cancer Institute	Head & Neck Surgery Unit, St Luc University Hospital
Dr An Claes	Researcher - doctor	Kom op tegen kanker
Prof Françoise Meunier	EORTC Director General	The European Organisation for Research and Treatment of Cancer (EORTC)
Dr Dominique de Valeriola	Board of directors	Belgian Cancer Registry
Harlinde De Schutter	Senior researcher	Belgian Cancer Registry
Dr Frank De Smet	Senior social security physician	Christian Health Insurance Funds - Medical management department
Dr Daphne Hompes	Oncological surgeon	University Hospital in Leuven
Prof de Lorenzo	ECPC President	ECPC
Kris Henau	Data Expert	Belgian Cancer Registry
Veerle Meynckens	Conseiller juridique	CPVP - La Commission de la protection de la vie privée
Dr Annalisa Trama	Epidemiologist	Istituto Nazionale dei Tumori: Fondazione IRCCS
Dr Gemma Gatta	Epidemiologist	Istituto Nazionale dei Tumori: Fondazione IRCCS
Laura Botta	Statistician	Istituto Nazionale dei Tumori: Fondazione IRCCS
Dr Riccardo Capocaccia	Mathematician	Istituto Nazionale dei Tumori: Fondazione IRCCS
Dr Liesbet Van Eycken	Managing director	Belgian Cancer Registry
Annick Vandenhooft	Research officer	Institut wallon de l'évaluation, de la prospective et de la statistique (IWEPS)
Elly Den Hond	Researcher	Belgian Cancer Centre
Benoit Mores	Cabinet Minister	Ministry of Social Affairs and Public Health
Geert Peuskens	Assistant director	Agency for Care and Health, Flemish Ministry for Welfare, Public Health and Family
Urbina Paz Montse	Scientific Collaborator	WIV-ISP service of health care surveillance
Anastassia Negrouk	Head of International Regulatory and Intergroup Office	EORTC
Dr Johan Abeloos	Oncological surgeon	St John's Hosptial, Antwerp
Dr Pol Specenier	Medical oncologist	University Hospital of Antwerp

Appendix 3: Rare cancer incidence in Belgium (estimated new cases, 2013)

Cancer entity	Crude incidence rate (100,000 per year)	Number of expected cases in Belgium (2013)
EPITHELIAL TUMOURS OF HYPOPHARYNX AND LARYNX	3<incidence<6 'Rare cancers'	720
EPITHELIAL TUMOURS OF OROPHARYNX		400
EPITHELIAL TUMOURS OF ORAL CAVITY AND LIP		587
EPITHELIAL TUMOURS OF OESOPHAGUS		836
EPITHELIAL TUMOURS OF LIVER AND INTRAEPATIC BILE TRACT (IBT)		575
EPITHELIAL TUMOURS OF GALLBLADDER AND EXTRAHEPATIC BILIARY TRACT (EBT)		555
EPITHELIAL TUMOURS OF LUNG		534
EPITHELIAL TUMOURS OF BREAST		490
EPITHELIAL TUMOURS OF CERVIX UTERI		631
EPITHELIAL TUMOURS OF OVARY AND FALLOPPIAN TUBE		856
TESTICULAR AND PARATESTICULAR CANCERS		348
SOFT TISSUE SARCOMA		557
NEUROENDOCRINE TUMOURS		420
CARCINOMAS OF THYROID GLAND		572
TUMOURS OF CENTRAL NERVOUS SYSTEM (CNS)		669
LYMPHOID DISEASES		2,169
ACUTE MYELOID LEUKEMIA AND RELATED PRECURSOR NEOPLASMS		466
MYELOPROLIFERATIVE NEOPLASMS		405
EPITHELIAL TUMOURS OF MAJOR SALIVARY GLANDS AND SALIVARY-GLAND TYPE TUMOURS	0.5<incidence<3	169
EPITHELIAL TUMOURS OF SMALL INTESTINE		96
EPITHELIAL TUMOURS OF ANAL CANAL		142
EPITHELIAL TUMOURS OF CORPUS UTERI		83
EPITHELIAL TUMOURS OF VULVA AND VAGINA		240
EPITHELIAL TUMOURS OF PROSTATE		77
EPITHELIAL TUMOURS OF PENIS		85
EPITHELIAL TUMOURS OF PELVIS AND URETER		197
EPITHELIAL TUMOURS OF BLADDER		82
MALIGNANT MESOTHELIOMA		270
MALIGNANT MELANOMA OF UVEA		84
BONE SARCOMA		96
MYELODYSPLASTIC SYNDROME AND MYELODYSPLASTIC/MYELOPROLIFERATIVE DISEASES		330
EPITHELIAL TUMOURS OF NASAL CAVITY AND SINUSES	Incidence<0.5	55
EPITHELIAL TUMOURS OF NASOPHARYNX		56

EPITHELIAL TUMOURS OF STOMACH	'Very rare cancers'	41
EPITHELIAL TUMOURS OF COLON		16
EPITHELIAL TUMOURS OF RECTUM		14
EPITHELIAL TUMOURS OF PANCREAS		9
EPITHELIAL TUMOUR OF TRACHEA		14
EPITHELIAL TUMOURS OF THYMUS		21
NON EPITHELIAL TUMOURS OF OVARY		28
TROPHOBLASTIC TUMOUR OF PLACENTA		2
EPITHELIAL TUMOURS OF KIDNEY		6
EPITHELIAL TUMOURS OF URETHRA		17
EPITHELIAL TUMOURS OF EYE AND ADNEXA		5
EPITHELIAL TUMOURS OF MIDDLE EAR		4
MALIGNANT MELANOMA OF MUCOSA AND EXTRACUTANEOUS		18
ADNEXAL CARCINOMA OF SKIN		39
NEUROBLASTOMA AND GANGLIONEUROBLASTOMA		12
NEPHROBLASTOMA		15
RETINOBLASTOMA		7
HEPATOBLASTOMA		3
PLEUROPULMONARY BLASTOMA		0
PANCREATOBLASTOMA		0
OLFACTORY NEUROBLASTOMA		4
ODONTOGENIC MALIGNANT TUMOURS		1
EXTRAGONADAL GERM CELL TUMOURS		13
GASTROINTESTINAL STROMAL SARCOMA		36
KAPOSI'S SARCOMA		29
CARCINOMAS OF PITUITARY GLAND		4
CARCINOMAS OF PARATHYROID GLAND		3
CARCINOMA OF ADRENAL GLAND		26
EMBRYONAL TUMORS OF CENTRAL NERVOUS SYSTEM (CNS)		22
HISTIOCYTIC AND DENDRITIC CELL NEOPLASMS		6

Appendix 4: Quality indicators and outcomes for soft tissue sarcoma of the extremities (a) and testicular cancers (b) in Belgium.

(a) Soft tissue sarcoma (extremities):

Criteria	Quality indicator	Findings from the high resolution study in Belgium
Diagnostic management	Percentage of patients with sarcoma undergoing preoperative scan and biopsy before treatment (MRI and/or CT locally and lung CT)	59% of sarcoma patients had a surgery without a biopsy. Many of these patients were treated in low volume hospitals
	Diagnosis done by an expert pathologist (or second opinion carried out in an expert centre if diagnosis is not carried out by an expert pathologist)	36% of cases had a second opinion requested. Of the hospitals requesting second opinions, the majority were low volume hospitals, and the hospitals providing the second opinion were high volume.
Adherence to clinical guidelines	Percentage of patients with low grade and R0 resection margin undergoing surgery alone.	Unknown.
	Percentage of patients with high grade and R0 resection undergoing surgical intervention and radiotherapy or radiotherapy and chemotherapy.	Unknown.
	Percentage of patients with R1 or R2 resection margin undergoing surgical re-intervention or, radiotherapy, or chemotherapy and radiotherapy.	Unknown.
Quality of surgery and radiotherapy	Complete tumour resection of definitive surgery	53% had R0 resection margins after the main surgery, 30% had R+ and data was missing in 17% of cases.
	Reoperation after primary definitive surgery	22% of surgeries needed re-operation after the primary surgery within 6 months.
Quality of pathology report after surgery	Percentage of pathology reports with a full set of core data items recorded according to the ESMO guidelines	98% of reports stated the site, 77% stated the size and 66% stated the grade of the tumour.
Availability of formalised multidisciplinary decision making and care	No indicators	No indicators collected by high resolution study because the information was not retrievable in the medical records
Participation in clinical and translational research	No indicators	No indicators collected by high resolution study because the information was not retrievable in the medical records

(b) Testicular cancer:

Criteria	Quality indicator	Findings from the high resolution study in Belgium
Timely start of treatment	Time to start treatment (time between definitive diagnosis by a pathologist and beginning of surgery or radiotherapy)	87% of patients started therapy in less than 3 days.
Adherence to clinical guidelines	Percentage of patients receiving orchiectomy followed by no treatment (active surveillance); chemotherapy; radiotherapy (seminoma only); RPLND (non-seminoma only)	29% of patients received radiation therapy after orchiectomy (in stage I seminomas).
	Percentage of patients treated with poor prognoses non-seminoma tumours	Unknown
	Percentage of patients receiving RPLND after combination of orchiectomy and chemotherapy in stage II or higher in seminomas and non-seminomas.	Unknown
Recurrence	Number and percentage of seminomas and non-seminoma patients with recurrences receiving high dose chemotherapy or RPLND	Unknown
	Number and percentage of seminomas and non-seminoma with recurrences during active surveillance	Unknown
Quality of pathology report after surgery	Percentage of pathology reports with a full set of core data items recorded according to the ESMO guidelines	97% of reports had information available on vascular invasion in the histological report.
		Vascular invasion was known for 85% of non-seminoma patients
Availability of formalised multidisciplinary decision making and care	Unknown	No indicators collected by high resolution study because the information was not retrievable in the medical records
Participation in clinical and translational research	Unknown	No indicators collected by high resolution study because the information was not retrievable in the medical records

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For further information, please see:

- RARECARENet - http://www.rarecarenet.eu/rarecarenet/
- European Cancer Patients Coalition (ECPC) - http://www.ecpc.org/

- Joint action on Cancer Control (CanCon) - http://www.cancercontrol.eu/index.php