RARECARENet country report

Bulgaria

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EUROPEAN CANCER PATIENT COALITION

BNCR

СБАЛО

Contents

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 begun 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:

- Estimation of European and country specific epidemiological indicators 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 volum**e' looked at 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 experts 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 at the National Hospital of Oncology in Sofia, Bulgaria on the 22nd May 2015.

The meeting gathered European and local experts on rare cancers (epidemiologists, oncologists, surgeons, and pathologists), cancer registry leads, patient organisations and representatives of the Public Health Institute, and the Ministry of Health, and was organised by the European Cancer Patient Coalition (ECPC) in collaboration with the Bulgarian national Cancer Registry and the National Hospital of Oncology.

(*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:

- Sharing the definition of rare cancers and describing the epidemiology of rare cancers in Bulgaria
- Discussing the most appropriate quality indicators for centres of expertise for specific rare cancers

- Discussing the importance of centralisation and the identification of centres of expertise for rare cancers in Bulgaria
- Identifying existing challenges in the management of rare cancers in Bulgaria.

2. The epidemiology of rare cancers in Bulgaria

Rare cancers account for 21% of all cancer diagnoses in Bulgaria

In Bulgaria 9,540 new cases of rare cancers were estimated for 2013. The crude incidence rate is 85.4 per 100 000 person-years (lower than Europe). This could be due different distribution of risk factors, different preventive/screening activities but also to the quality of the pathological diagnosis. The pathological diagnosis with a morphology not specified (NOS) made up approximately 20% of the diagnoses in Bulgaria. This is important because rare cancers are defined on the basis of the histotype thus, the higher the NOS morphologies, the lower the potential rare cancers incidence rate.

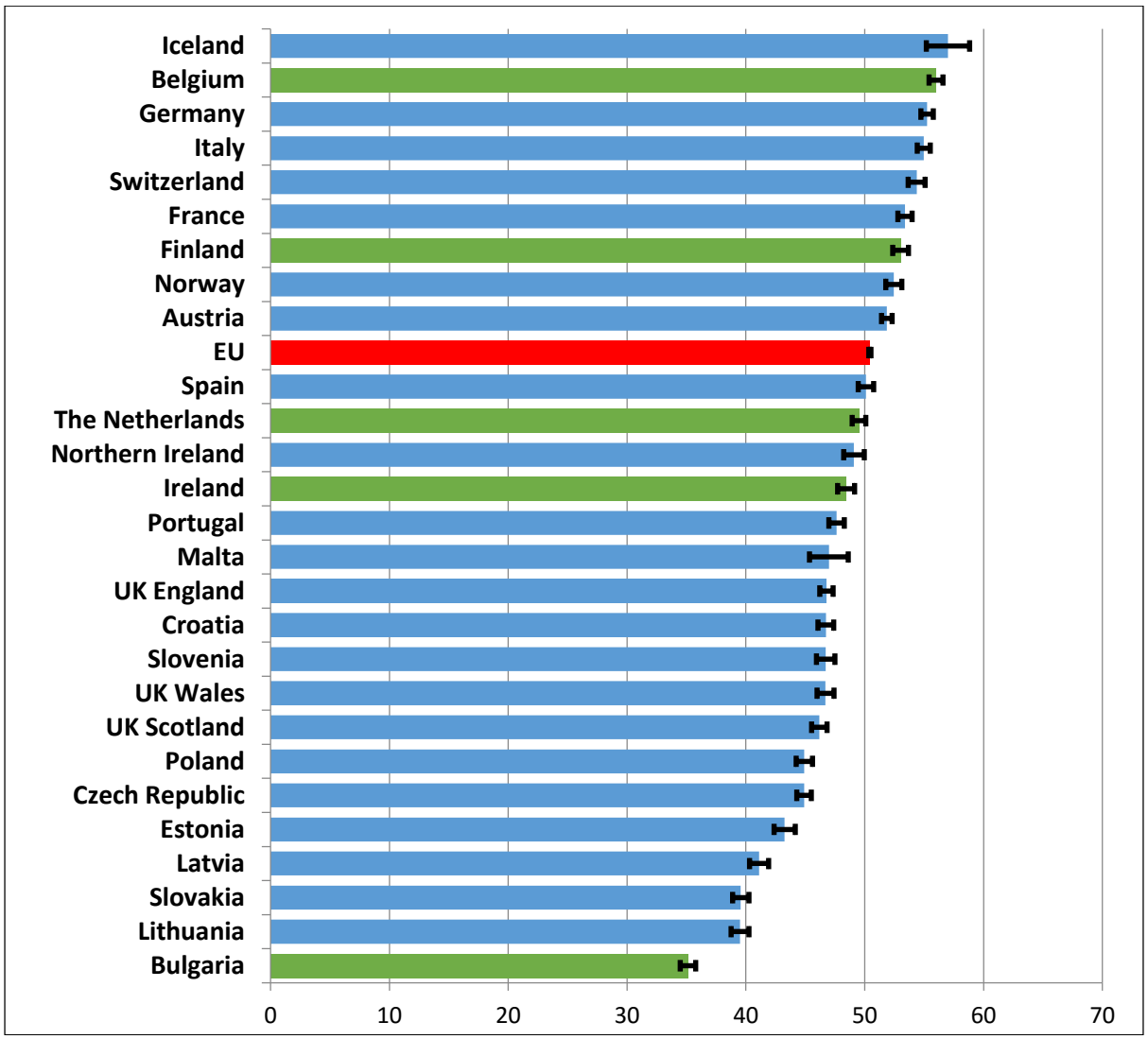
The estimated number of new rare cancer cases for 2013 was 9540 in Bulgaria. The majority of cancers (56.6% of all diagnoses) are designated very rare – with incidence less than 1 per 100 000. Three cancers, which are rare at the European level, have incidence higher than 6 per 100 000 (squamous cell carcinoma of cervix uteri, squamous cell carcinoma of larynx and adenocarcinoma of ovary).

The survival of people who are diagnosed with a rare cancer is lower than that in common cancers.

Using the RARECARE database, survival analysis for rare cancers was conducted per country. Data from Bulgaria follow a similar trend observed across all countries: survival rates for rare cancers are lower than those for common cancers.

Additionally, survival rates for rare cancers in Bulgaria are lower than the European average, as demonstrated by Figure 1.

Figure 1- 5-year survival rates for rare cancers shown in Bulgaria and other European countries. Survival is adjusted by age and case mix. Countries studied in detail by RARECARENet are shown in green.



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 quality 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 rare cancers are presented in **Table 1**. These aspects are important to consider in identifying and evaluating centres of expertise. Specific indicators, based on these key aspects, relevant to two particular rare cancers (soft tissue sarcomas and head and neck 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 the use of inadequate diagnostic procedures, incorrect or delayed diagnosis and poor staging procedures. Additionally the referral pathway is not always clear, since centres dedicated to rare cancers may not exist.
Quality of care	Lack of knowledge and clinical expertise among health 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 treatment by a multidisciplinary team, as it provides a higher quality of care for patients.
Quality of pathological report after surgery	Pathological reports are essential for planning appropriate treatment post-surgery. 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 post-surgical 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 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 and develop alternative study designs and approaches to with the aim to improve accuracy and standardisation of treatment for rare cancers. [1]

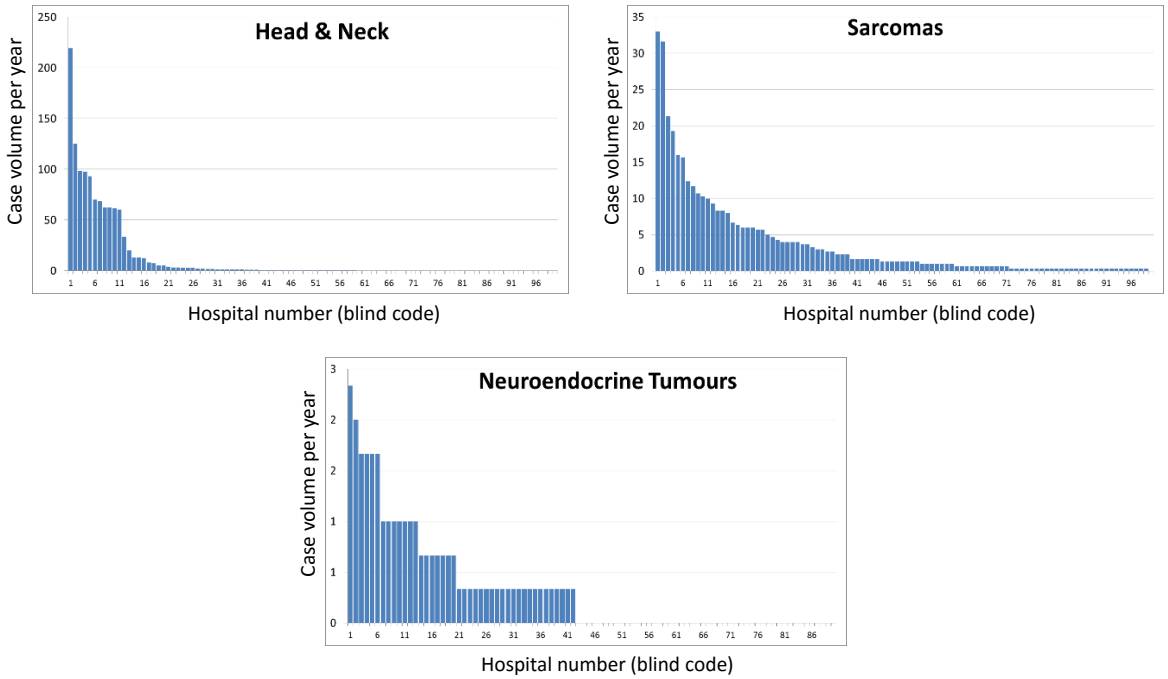
4. Treatment centres for rare cancers in Bulgaria

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 cases. Currently in Bulgaria, cancer management is spread over 150 hospitals, challenging resource allocation and provision of expert clinicians. Increasing the level of centralisation for rare cancer care will therefore be key to improving outcomes, and is a key recommendation in the national rare disease strategy.[3] In fact, a list of centres of expertise for rare diseases, including cancer, is being developed by the ministry of health to encourage the centralisation of care.

Rare cancers differ in their degree of centralisation in Bulgaria, as is illustrated in **Figure 2.** Head and neck cancer treatment is more centralised than soft tissue sarcoma and neuroendocrine tumours.

Results from the pilot study in Bulgaria, which assessed the relationship between hospital volume and outcomes of treatment, found that patients with head and neck cancers have an approximately 60% higher risk of dying if treated in a low volume hospital as compared to a high volume hospital. Despite this, 17% of patients are treated in low volume hospitals (with less than 20 patients/year).

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



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.

It was beyond the scope of the RARECARENet project to determine specific centres of expertise for rare cancers in Bulgaria, therefore it focused on developing quality criteria for their selection and a discussion of centres providing treatment for rare cancers. The Bulgarian National Cancer Registry provided a list of hospitals in which rare cancer patients have been treated, according to the information from the registry database, featured in **Appendix 5.** Rare cancer patients are currently treated in both specialist cancer hospitals as well as surgery, radiotherapy and systemic therapy units within general hospitals.

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

A. General challenges in the management of rare cancers in Bulgaria

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 Bulgaria for the management of rare cancers confirm the relevance of the quality criteria chosen and the importance of centralised care. They included:

- **Decentralised treatment,** impacting negatively on patient outcomes
- **No designation of Centres of Expertise** to encourage centralisation of care
- **Lack of consistent standards of care**, creating inequalities in the care provided to patients
- **Pathways for second opinions not well established**
- **Limited experience from pathologists and poorly funded laboratories,** contributing to delays in diagnosis and/or misdiagnosis
- **Limited research base on rare cancers** and inadequate translation of this research into policy.
- **Incomplete medical records,** which among other challenges, may create difficulties when monitoring indicators for guideline adherence.

B. Specific challenges in the management of soft tissue sarcomas, head and neck cancers and neuroendocrine cancers.

The following challenges were highlighted specifically for the management of sarcomas, neuroendocrine and head and neck cancers. Findings from the high resolution study are presented when relevant.

*(Further details from the High Resolution Study can be found in **Appendix 4)***

Table 2: Main challenges in the management of soft tissue sarcoma, head and neck, and neuroendocrine cancers in Bulgaria.

i) Soft tissue sarcomas

Area for improvement	Identified challenges
Pathology reporting	Only 12% of patients have a complete set of information in their pathology reports. Limited access to facilities and professional education, (e.g. WHO Blue Books) which challenges adequate and timely diagnosis.
Imaging	Only 52% of the patients had preoperative imaging and only 32% with appropriate diagnostic tool (CT or MRI).
Radiotherapy	Poor access (long waiting lists) to radiotherapy facilities results in limited number of patients receiving this treatment, contrary to ESMO guideline recommendations for patients with high grade and R0 resection or patients with R1 and R2.
Centralisation	Treatment is often scattered across many treatment centres, as illustrated in **Figure 2.** 25% of patients are treated in low volume hospitals (less than 5 patients a year).
Multidisciplinary teams	Discussion between surgeons and pathologists is poor, and may be a cause of poor quality pathology reporting. Improved communication between pathologists, surgeons and other health care professionals will improve the quality of care for patients.

ii) Head and neck cancers

Area for improvement	Identified challenges

Diagnostic management	58% of patients are diagnosed at an advanced stage. The majority of patients had surgery without a biopsy, contrary to ESMO guideline recommendations.
Multidisciplinary teams	Improved communication between pathologists, surgeons and other health care professionals through the implementation of multidisciplinary teams will improve the quality of care for patients.

iv) Neuroendocrine tumours

Area for improvement	**Identified challenges**
Diagnostic management	There are few pathologists with experience in neuroendocrine tumours, which may result in misdiagnosis. Most neuroendocrine patients do not have a preoperative morphological diagnosis, and diagnosis occurs only after surgery. Additionally, there is poor access to adequate laboratory diagnostic facilities and tests, further challenging the diagnosis of this (and other rare cancers).
Pathology reporting	Large proportion of individuals are missing resection data. Access to WHO Blue Books and training for pathologists is poor, contributing to poor quality pathology reports.
Quality of care	The majority of patients had surgery without chemotherapy, against guideline recommendations.

6. Recommendations for the future

Discussions during the meeting identified a number of key recommendations for the improved management of rare cancers in Bulgaria. These are summarised below for rare cancers in general (A), and specifically for soft tissue sarcomas, head and neck, and neuroendocrine cancers (B).

A. 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.
    - **Improve the quality of medical documentation regarding details of diagnostic procedures and treatment**

2. Centralise care to centres of expertise:

    - **Designate centres of expertise** to which rare cancer care is centralised
    - **Ensure a monitoring and evaluation system for the centres,** with improvement initiatives to maintain high quality care.

3. 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.

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

    - **Use a population-based cancer registry** as 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 Bulgaria
    - **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.**

B. Cancer-specific recommendations

Soft tissue sarcoma:

- **Ensure diagnosis is always performed by an expert pathologist**, if this is not possible, the patient should be referred to an expert pathologist for a second opinion
- **Create clear and transparent pathways for second opinions,** and ensure that these referrals are properly reimbursed
- **Define centres of expertise for sarcoma treatment** to which treatment should be centralised, allowing more patients to be seen in high volume hospitals.
- **Improve pathology facilities and the availability of Bulgarian translations of the WHO Blue Book** to improve the quality of histological diagnoses**.**

Head and neck cancers:

- **Ensure diagnosis before surgery and a complete pathological report,** which includes information on resection status and tumour invasion.

Neuroendocrine tumours:

- **Ensure adequate pathological diagnosis** to avoid misclassification
- **Improve training for pathologists,** particularly regarding the use modern diagnostic methods for rare cancers.

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 and list of participants for the Sofia meeting on Rare Cancers

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

May22nd, 2015
Location: National Hospital of Oncology, Sofia, Bulgaria.

Time	Topic	Responsibility
9:00 – 10:00	Welcome and introduction round	Director of the Hospital Director of Cancer Registry
10:00 – 10:45	RARECARE and the Burden of Rare Cancers	Gemma Gatta, RARECAREnet
10:45 – 11:05	Burden of Rare Cancers in Bulgaria	Nadya Dimitrova
11:05 – 11:30	Questions	
11:30 – 11:45	Coffee break	
11:45 – 12:30	RARECAREnet project and quality criteria	Annalisa Trama, RARECAREnet
12:30 – 13:15	Lunch	
13:15 – 14:00	Results of the high resolution studies	Nadya Dimitrova
14:00 – 14:45	Results of the volume analyses of the country	Riccardo Capoccacia, RARECAREnet
14:45 – 15:15	Discussion on the level of centralization and hospital volume for the specific country	Chaired by Annalisa Trama
15:15 – 15:30	Patients perspective - Centres of expertise	ECPC, supported by the Bulgarian Patient Association
15:30 – 16:30	Possible conclusions, way forward here we have to focus the discussion on how to identify the centres, what the country is intended to do?	Chaired by Annalisa Trama
	End, Close of the Day	

Participants:

Name	Position	Institution
Irina Kovacheva	Member of the Commission on Rare Diseases	Ministry of Health
Valentin Angelov	Director	National Oncological Hospital
ZdravkaValerianova	Director	Bulgarian National Cancer Registry
PlamenTaushanov	Chairman	BULGARIAN ASSOCIATION FOR PROTECTION OF PATIENTS
Galina Kurteva	Head of Chemotherapy department	National Oncological Hospital
Natalia Chilingirova	Chemotherapist	National Oncological Hospital
Ivan Gavrilov	Head of the Thoracic Surgery department	National Oncological Hospital
Iva Gavrilova	Surgeon	National Oncological Hospital
TihomirDikov	Pathologist	University Hospital "Alexandrovska", Sofia
VeselaIvanova	Pathologist	University Hospital "Alexandrovska", Sofia
NatashkaDanova	Head of health analysis department	Public Health Institute
TsonkaMiteva	Rare diseases registry	Rare diseases institute
Diana Kirova	Head of the regional cancer registry	Regional Oncology Center
MinkaYordanova	Database manager	Bulgarian National Cancer Registry
Tinka Kuneva	Registrar	Bulgarian National Cancer Registry
Teodora Grozeva	Registrar	Bulgarian National Cancer Registry
TrayanAtanasov	Database manager	Bulgarian National Cancer Registry
Lilyana Uzunova	Registrar	Bulgarian National Cancer Registry
YovkaPetkova	Registrar	Bulgarian National Cancer Registry
NadyaDimitrova	Epidemiologist	Bulgarian National Cancer Registry
Gemma Gatta	Epidemiologist	Istitutodeitumori
Annalisa Trama	Epidemiologist	Istitutodeitumori
Riccardo Capocaccia	Mathematician	Istitutodeitumori
Laura Botta	Statistician	Istitutodeitumori
Sergio Sandrucci	Surgeon	European Society of Surgical Oncology

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

Tier	Cancer entity	Bulgaria			
		Crude Incidence rate x 100,000/year	95% Confidence Interval		Estimated new cases at 2013*
			lower bound	upper bound	
1	**EPITHELIAL TUMOURS OF NASAL CAVITY AND SINUSES**	0,48040	0,42766	0,53786	38
2	Squamous cell carcinoma with variants of nasal cavity and sinuses	0,35112	0,30626	0,40072	29
2	Lymphoepithelial carcinoma of nasal cavity and sinuses	0,00160	0,00004	0,00889	0
2	Undifferentiated carcinoma of nasal cavity and sinuses	0,02234	0,01222	0,03749	2
2	Intestinal type adenocarcinoma of nasal cavity and sinuses	0,00000	0,00000	0,00589	0
1	**EPITHELIAL TUMOURS OF NASOPHARYNX**	0,86345	0,79221	0,93937	38
2	Squamous cell carcinoma with variants of nasopharynx	0,76609	0,69908	0,83779	29
2	Papillary adenocarcinoma of nasopharynx	0,00160	0,00004	0,00889	0
1	**EPITHELIAL TUMOURS OF MAJOR SALIVARY GLANDS AND SALIVARY-GLAND TYPE TUMOURS**	1,27363	1,18678	1,36515	115
2	Epithelial tumours of major salivary glands	1,02624	0,94844	1,10872	80
2	Salivary gland type tumours of head and neck	0,24738	0,20997	0,28954	36
1B	**EPITHELIAL TUMOURS OF HYPOPHARYNX AND LARYNX**	7,51247	7,29938	7,73022	497
2	Squamous cell carcinoma with variants of hypopharynx	0,76449	0,69756	0,83612	106
2	Squamous cell carcinoma with variants of larynx	6,74798	6,54609	6,95451	391
1	**EPITHELIAL TUMOURS OF OROPHARYNX**	2,30944	2,19197	2,43158	276
2	Squamous cell carcinoma with variants of oropharynx	2,09398	1,98219	2,21043	259
1	**EPITHELIAL TUMOURS OF ORAL CAVITY AND LIP**	5,31954	5,14046	5,50327	401
2	Squamous cell carcinoma with variants of oral cavity	2,19293	2,07850	2,31203	293
2	Squamous cell carcinoma with variants of lip	2,74995	2,62162	2,88293	87
1B	**EPITHELIAL TUMOURS OF OESOPHAGUS**	1,19382	1,10979	1,28253	570
2	Squamous cell carcinoma with variants of oesophagus	0,80120	0,73264	0,87446	286
2	Adenocarcinoma with variants of oesophagus	0,36389	0,31819	0,41432	279
2	Salivary gland type tumours of oesophagus	0,00160	0,00004	0,00889	0
2	Undifferentiated carcinoma of oesophagus	0,02713	0,01581	0,04344	4
1B	**EPITHELIAL TUMOURS OF STOMACH**	0,84430	0,77387	0,91941	28
2	Squamous cell carcinoma with variants of stomach	0,07980	0,05923	0,10521	10
2	Salivary gland-type tumours of stomach	0,00000	0,00000	0,00589	0
2	Undifferentiated carcinoma of stomach	0,76449	0,69756	0,83612	18
1	**EPITHELIAL TUMOURS OF SMALL INTESTINE**	0,36868	0,32267	0,41942	66
2	Adenocarcinoma with variants of small intestine	0,17397	0,14284	0,20986	50
2	Squamous cell carcinoma with variants of small intestine	0,00160	0,00004	0,00889	1
1B	**EPITHELIAL TUMOURS OF COLON**	0,04628	0,03100	0,06647	11
2	Squamous cell carcinoma with variants of colon	0,03511	0,02200	0,05316	2
2	Fibromixoma and low grade mucinous adenocarcinoma of the appendix	0,01117	0,00449	0,02302	9
1B	**EPITHELIAL TUMOURS OF RECTUM**	0,08778	0,06613	0,11426	10

2	Squamous cell carcinoma with variants of rectum	0,08778	0,06613	0,11426	10
1	**EPITHELIAL TUMOURS OF ANAL CANAL**	0,83472	0,76470	0,90942	97
2	Squamous cell carcinoma with variants of anal canal	0,26813	0,22912	0,31188	68
2	Adenocarcinoma with variants of anal canal	0,48519	0,43218	0,54291	22
2	Paget's disease of anal canal	0,00000	0,00000	0,00589	0
1B	**EPITHELIAL TUMOURS OF PANCREAS**	0,06224	0,04426	0,08509	6
2	Squamous cell carcinoma with variants of pancreas	0,02713	0,01581	0,04344	2
2	Acinar cell carcinoma of pancreas	0,03352	0,02075	0,05123	2
2	Mucinous cystadenocarcinoma of pancreas	0,00160	0,00004	0,00889	1
2	Intraductal papillary mucinous carcinoma invasive of pancreas	0,00000	0,00000	0,00589	1
2	Solid pseudopapillary carcinoma of pancreas	0,00000	0,00000	0,00589	0
2	Serous cystadenocarcinoma of pancreas	0,00000	0,00000	0,00589	0
2	Carcinoma with osteoclast-like giant cells of pancreas	0,00000	0,00000	0,00589	0
1B	**EPITHELIAL TUMOURS OF LIVER AND INTRAEPATIC BILE TRACT (IBT)**	2,14984	2,03655	2,26779	400
2	Hepatocellular carcinoma of Liver and IBT	1,69657	1,59610	1,80171	277
2	Hepatocellular carcinoma, fibrolamellar of liver and IBT	0,02873	0,01703	0,04540	2
2	Cholangiocarcinoma of IBT	0,16758	0,13707	0,20287	83
2	Adenocarcinoma with variants of liver and IBT	0,21865	0,18358	0,25849	36
2	Undifferentiated carcinoma of liver and IBT	0,03032	0,01826	0,04736	1
2	Squamous cell carcinoma with variants of liver and IBT	0,00319	0,00039	0,01153	1
2	Bile duct cystadenocarcinoma of IBT	0,00479	0,00099	0,01399	0
1	**EPITHELIAL TUMOURS OF GALLBLADDER AND EXTRAHEPATIC BILIARY TRACT (EBT)**	3,39633	3,25355	3,54377	382
2	Adenocarcinoma with variants of gallbladder	1,25447	1,16829	1,34533	117
2	Adenocarcinoma with variants of EBT	0,56659	0,50917	0,62870	124
2	Squamous cell carcinoma of gallbladder and EBT	0,02713	0,01581	0,04344	3
1	**EPITHELIAL TUMOUR OF TRACHEA**	0,13247	0,10551	0,16422	10
2	Squamous cell carcinoma with variants of trachea	0,07182	0,05239	0,09610	6
2	Adenocarcinoma with variants of trachea	0,01277	0,00551	0,02516	1
2	Salivary gland type tumours of trachea	0,00958	0,00351	0,02084	1
1B	**EPITHELIAL TUMOURS OF LUNG**	2,39084	2,27129	2,51505	377
2	Adenosquamous carcinoma of lung	0,57297	0,51523	0,63542	25
2	Large cell carcinoma of lung	1,49707	1,40278	1,59602	329
2	Salivary gland type tumours of lung	0,16918	0,13851	0,20462	5
2	Sarcomatoid carcinoma of lung	0,15162	0,12267	0,18535	18
1	**EPITHELIAL TUMOURS OF THYMUS**	0,12130	0,09557	0,15182	15
2	Malignant thymoma	0,10055	0,07726	0,12865	12
2	Squamous cell carcinoma of thymus	0,00160	0,00004	0,00889	1
2	Undifferentiated carcinoma of thymus	0,00160	0,00004	0,00889	0
2	Lymphoepithelial carcinoma of thymus	0,00319	0,00039	0,01153	0
2	Adenocarcinoma with variants of thymus	0,00319	0,00039	0,01153	0
1B	**EPITHELIAL TUMOURS OF BREAST**	3,14895	3,01152	3,29104	347
2	Mammary Paget's disease of breast	0,23462	0,19822	0,27576	35

2	Special types of adenocarcinoma of breast	2,39722	2,27751	2,52160	258
2	Metaplastic carcinoma of breast	0,02713	0,01581	0,04344	8
2	Salivary gland type tumours of breast	0,02394	0,01340	0,03949	5
2	Epithelial tumour of male breast	1,04788	0,93603	1,16941	44
1B	**EPITHELIAL TUMOURS OF CORPUS UTERI**	0,69906	0,63511	0,76769	62
2	Squamous cell carcinoma with variants of corpus uteri	0,11970	0,09415	0,15005	5
2	Adenoid cystic carcinoma of corpus uteri	0,00160	0,00004	0,00889	0
2	Clear cell adenocarcinoma, Not Otherwise Specified (NOS) of corpus uteri	0,31601	0,27353	0,36323	14
2	Serous (papillary) carcinoma of corpus uteri	0,00000	0,00000	0,00589	7
2	Mullerian mixed tumour of corpus uteri	0,26175	0,22322	0,30502	35
1B	**EPITHELIAL TUMOURS OF CERVIX UTERI**	13,02035	12,73932	13,30601	444
2	Squamous cell carcinoma with variants of cervix uteri	11,82173	11,55403	12,09408	369
2	Adenocarcinoma with variants of cervix uteri	1,10764	1,02675	1,19320	71
2	Undifferentiated carcinoma of cervix uteri	0,07661	0,05649	0,10157	3
2	Mullerian mixed tumour of cervix uteri	0,01436	0,00657	0,02727	1
1B	**EPITHELIAL TUMOURS OF OVARY AND FALLOPPIAN TUBE**	7,68165	7,46615	7,90180	636
2	Adenocarcinoma with variants of ovary	6,16224	5,96938	6,35974	511
2	Mucinous adenocarcinoma of ovary	1,15392	1,07133	1,24119	64
2	Clear cell adenocarcinoma of ovary	0,20110	0,16752	0,23943	26
2	Primary peritoneal serous/papillary carcinoma of ovary	0,00000	0,00000	0,00589	7
2	Mullerian mixed tumour of ovary	0,04469	0,02970	0,06459	13
2	Adenocarcinoma with variant of falloppian tube	0,11970	0,09415	0,15005	15
1	**NON EPITHELIAL TUMOURS OF OVARY**	0,49955	0,44574	0,55808	19
2	Sex cord tumours of ovary	0,36709	0,32117	0,41772	10
2	Malignant/Immature teratomas of ovary	0,04309	0,02840	0,06270	4
2	Germ cell tumour of ovary	0,08938	0,06751	0,11606	5
1	**EPITHELIAL TUMOURS OF VULVA AND VAGINA**	1,75243	1,65030	1,85923	165
2	Squamous cell carcinoma with variants of vulva and vagina	1,56410	1,46770	1,66518	142
2	Adenocarcinoma with variants of vulva and vagina	0,05267	0,03625	0,07397	6
2	Paget s disease of vulva and vagina	0,00160	0,00004	0,00889	4
2	Undifferentiated carcinoma of vulva and vagina	0,01756	0,00876	0,03141	0
1	**TROPHOBLASTIC TUMOUR OF PLACENTA**	0,04150	0,02711	0,06080	2
2	Choriocarcinoma of placenta	0,04150	0,02711	0,06080	2
1B	**EPITHELIAL TUMOURS OF PROSTATE**	0,36868	0,32267	0,41942	52
2	Squamous cell carcinoma with variants of prostate	0,04628	0,03100	0,06647	2
2	Infiltrating duct carcinoma of prostate	0,24260	0,20556	0,28437	45
2	Transitional cell carcinoma of prostate	0,07821	0,05786	0,10339	5
2	Salivary gland type tumours of prostate	0,00160	0,00004	0,00889	1
1	**TESTICULAR AND PARATESTICULAR CANCERS**	2,20411	2,08938	2,32350	240
2	Paratesticular adenocarcinoma with variants	0,00000	0,00000	0,00589	0
2	Non seminomatous testicular cancer	0,87941	0,80750	0,95600	90
2	Seminomatous testicular cancer	1,09008	1,00985	1,17499	134
2	Spermatocytic seminoma	0,07342	0,05375	0,09793	3
2	Teratoma with malignant transformation	0,00000	0,00000	0,00589	0

2	Testicular sex cord cancer	0,00958	0,00351	0,02084	2
1	**EPITHELIAL TUMOURS OF PENIS**	0,57776	0,51977	0,64045	56
2	Squamous cell carcinoma with variants of penis	0,51552	0,46082	0,57491	52
2	Adenocarcinoma with variants of penis	0,00319	0,00039	0,01153	0
1B	**EPITHELIAL TUMOURS OF KIDNEY**	0,09736	0,07447	0,12506	4
2	Squamous cell carcinoma spindle cell type of kidney	0,01436	0,00657	0,02727	1
2	Squamous cell carcinoma with variants of kidney	0,08299	0,06198	0,10883	3
1	**EPITHELIAL TUMOURS OF PELVIS AND URETER**	0,74534	0,67927	0,81611	137
2	Transitional cell carcinoma of pelvis and ureter	0,60489	0,54552	0,66896	122
2	Squamous cell carcinoma with variants of pelvis and ureter	0,02394	0,01340	0,03949	2
2	Adenocarcinoma with variants of pelvis and ureter	0,05107	0,03493	0,07210	2
1	**EPITHELIAL TUMOURS OF URETHRA**	0,02554	0,01460	0,04147	11
2	Transitional cell carcinoma of urethra	0,01436	0,00657	0,02727	8
2	Squamous cell carcinoma with variants of urethra	0,00319	0,00039	0,01153	2
2	Adenocarcinoma with variants of urethra	0,00319	0,00039	0,01153	1
1B	**EPITHELIAL TUMOURS OF BLADDER**	0,50594	0,45177	0,56481	56
2	Squamous cell carcinoma with variants of bladder	0,29207	0,25129	0,33759	30
2	Adenocarcinoma with variants of bladder	0,21227	0,17773	0,25157	25
2	Salivary gland type tumours of bladder	0,00160	0,00004	0,00889	0
1	**EPITHELIAL TUMOURS OF EYE AND ADNEXA**	0,08459	0,06336	0,11064	4
2	Squamous cell carcinoma with variants of eye and adnexa	0,06224	0,04426	0,08509	2
2	Adenocarcinoma with variants of eye and adnexa	0,01596	0,00765	0,02935	1
1	**EPITHELIAL TUMOURS OF MIDDLE EAR**	0,02075	0,01105	0,03548	3
2	Squamous cell carcinoma with variants middle ear	0,01915	0,00990	0,03346	2
2	Adenocarcinoma with variants of middle ear	0,00000	0,00000	0,00589	0
1	**MALIGNANT MESOTHELIOMA**	0,41816	0,36905	0,47198	186
2	Mesothelioma of pleura and pericardium	0,35751	0,31222	0,40752	159
2	Mesothelioma of peritoneum and tunica vaginalis	0,04948	0,03362	0,07023	11
1	**MALIGNANT MELANOMA OF MUCOSA AND EXTRACUTANEOUS**	0,03032	0,01826	0,04736	12
2	Malignant melanoma of mucosa and extracutaneous	0,03032	0,01826	0,04736	12
1	**MALIGNANT MELANOMA OF UVEA**	0,36549	0,31968	0,41602	59
2	Malignant melanoma of uvea	0,36549	0,31968	0,41602	59
1	**ADNEXAL CARCINOMA OF SKIN**	0,26494	0,22617	0,30845	25
2	Adnexal carcinoma of skin	0,26494	0,22617	0,30845	25
1	**NEUROBLASTOMA AND GANGLIONEUROBLASTOMA**	0,06065	0,04292	0,08325	6
2	Neuroblastoma and ganglioneuroblastoma	0,06065	0,04292	0,08325	6
1	**NEPHROBLASTOMA**	0,07182	0,05239	0,09610	8
2	Nephroblastoma	0,07182	0,05239	0,09610	8
1	**RETINOBLASTOMA**	0,03511	0,02200	0,05316	4
2	Retinoblastoma	0,03511	0,02200	0,05316	4
1	**HEPATOBLASTOMA**	0,00798	0,00259	0,01862	1
2	Hepatoblastoma	0,00798	0,00259	0,01862	1
1	**PLEUROPULMONARY BLASTOMA**	0,00000	0,00000	0,00589	0
2	Pleuropulmonary blastoma	0,00000	0,00000	0,00589	0

1	**PANCREATOBLASTOMA**	0,00798	0,00259	0,01862	0
2	Pancreatoblastoma	0,00798	0,00259	0,01862	0
1	**OLFACTORY NEUROBLASTOMA**	0,03032	0,01826	0,04736	3
2	Olfactory neuroblastoma	0,03032	0,01826	0,04736	3
1	**ODONTOGENIC MALIGNANT TUMOURS**	0,00000	0,00000	0,00589	0
2	Odontogenic malignant tumours	0,00000	0,00000	0,00589	0
1	**EXTRAGONADAL GERM CELL TUMOURS**	0,05267	0,03625	0,07397	8
2	Non seminomatous germ cell tumours	0,02873	0,01703	0,04540	4
2	Seminomatous germ cell tumors	0,00160	0,00004	0,00889	1
2	Germ cell tumors of Central Nervous System (CNS)	0,01436	0,00657	0,02727	2
1	**SOFT TISSUE SARCOMA**	4,56622	4,40042	4,73667	383
2	Soft tissue sarcoma of head and neck	0,26813	0,22912	0,31188	21
2	Soft tissue sarcoma of limbs	1,00390	0,92697	1,08551	89
2	Soft tissue sarcoma of superficial trunk	0,50753	0,45328	0,56650	41
2	Soft tissue sarcoma of mediastinum	0,03511	0,02200	0,05316	2
2	Soft tissue sarcoma of heart	0,00798	0,00259	0,01862	1
2	Soft tissue sarcoma of breast	0,11970	0,09415	0,15005	15
2	Soft tissue sarcoma of uterus	0,75173	0,68536	0,82278	45
2	Other soft tissue sarcomas of genitourinary tract	0,16279	0,13274	0,19762	17
2	Soft tissue sarcoma of viscera	0,38145	0,33462	0,43300	32
2	Soft tissue sarcoma of paratestis	0,01756	0,00876	0,03141	3
2	Soft tissue sarcoma of retroperitoneum and peritoneum	0,54903	0,49254	0,61023	26
2	Soft tissue sarcoma of pelvis	0,21546	0,18065	0,25503	16
2	Soft tissue sarcoma of skin	0,17077	0,13995	0,20636	24
2	Soft tissue sarcoma of paraorbit	0,01756	0,00876	0,03141	1
2	Soft tissue sarcoma of brain and other parts of nervous system	0,14364	0,11551	0,17656	14
2	Embryonal rhabdomyosarcoma of soft tissue	0,03352	0,02075	0,05123	3
2	Alveolar rhabdomyosarcoma of soft tissue	0,03032	0,01826	0,04736	2
2	Ewing's sarcoma of soft tissue	0,00958	0,00351	0,02084	4
1	**BONE SARCOMA**	0,83632	0,76623	0,91109	63
2	Osteogenic sarcoma	0,22185	0,18650	0,26194	15
2	Chondrogenic sarcomas	0,28888	0,24833	0,33417	21
2	Notochordal sarcomas, chordoma	0,03990	0,02582	0,05890	4
2	Vascular sarcomas	0,00000	0,00000	0,00589	1
2	Ewing's sarcoma	0,14045	0,11264	0,17304	8
2	Epithelial tumours, adamantinoma	0,01915	0,00990	0,03346	1
2	Other high grade sarcomas (fibrosarcoma, malignant fibrous histiocytoma)	0,03032	0,01826	0,04736	2
1	**GASTROINTESTINAL STROMAL SARCOMA**	0,00000	0,00000	0,00589	26
2	Gastrointestinal stromal sarcoma	0,00000	0,00000	0,00589	26
1	**KAPOSI'S SARCOMA**	0,09895	0,07587	0,12685	20
2	Kaposi's sarcoma	0,09895	0,07587	0,12685	20
1	**NEUROENDOCRINE TUMOURS**	0,78843	0,72043	0,86113	294
2	GEP, Well differentiated not functing endocrine carcinoma of pancreas and digestive system	0,28090	0,24093	0,32560	84

2	GEP, Well differentiated functing endocrine carcinoma of pancreas and digestive system	0,01596	0,00765	0,02935	2
2	GEP, Poorly differentiated endocrine carcinoma of pancreas and digestive system	0,01915	0,00990	0,03346	56
2	GEP, Mixed endocrine-exocrine carcinoma of pancreas and digestive system	0,02234	0,01222	0,03749	1
2	Endocrine carcinoma of thyroid gland	0,09576	0,07308	0,12326	20
2	Neuroendocrine carcinoma of skin	0,00958	0,00351	0,02084	16
2	Typical and atypical carcinoid of the lung	0,11651	0,09132	0,14649	32
2	Neuroendocrine carcinoma of other sites	0,15641	0,12698	0,19061	77
2	Pheochromocytoma, malignant	0,03352	0,02075	0,05123	3
2	Paraganglioma	0,03830	0,02454	0,05699	2
1	**CARCINOMAS OF PITUITARY GLAND**	0,01436	0,00657	0,02727	3
2	Carcinomas of pituitary gland	0,01436	0,00657	0,02727	3
1	**CARCINOMAS OF THYROID GLAND**	2,92072	2,78842	3,05768	400
2	Carcinomas of thyroid gland	2,92072	2,78842	3,05768	400
1	**CARCINOMAS OF PARATHYROID GLAND**	0,01277	0,00551	0,02516	2
2	Carcinomas of parathyroid gland	0,01277	0,00551	0,02516	2
1	**CARCINOMA OF ADRENAL GLAND**	0,24898	0,21144	0,29126	18
2	Carcinoma of adrenal gland	0,24898	0,21144	0,29126	18
1B	**TUMOURS OF CENTRAL NERVOUS SYSTEM (CNS)**	4,56143	4,39572	4,73179	471
2	Astrocytic tumours of CNS	3,76821	3,61773	3,92334	411
2	Oligodendroglial tumours of CNS	0,28888	0,24833	0,33417	30
2	Ependymal tumours of CNS	0,10853	0,08428	0,13759	15
2	Neuronal and mixed neuronal-glial tumors	0,00000	0,00000	0,00589	0
2	Choroid plexus carcinoma of CNS	0,00479	0,00099	0,01399	0
2	Malignant meningiomas	0,39103	0,34359	0,44318	14
1	**EMBRYONAL TUMORS OF CENTRAL NERVOUS SYSTEM (CNS)**	0,14364	0,11551	0,17656	13
2	Embryonal tumours of Central Nervous System (CNS)	0,14364	0,11551	0,17656	13
1B	**LYMPHOID DISEASES**	7,46779	7,25533	7,68489	1487
2	Hodgkin lymphoma, classical	2,08281	1,97132	2,19896	182
2	Hodgkin lymphoma nodular lymphocyte predominance	0,00638	0,00174	0,01635	7
2	Precursor B/T lymphoblastic leukemia/lymphoma (and Burkitt leukemia/lymphoma)	1,15073	1,06826	1,23788	102
2	T cutaneous lymphoma (Sezary syn, Mycosis fung)	0,15801	0,12842	0,19237	29
2	Other T cell lymphomas and NK cell neoplasms	0,13407	0,10694	0,16598	51
2	Diffuse B lymphoma	1,22894	1,14366	1,31889	363
2	Follicular B lymphoma	0,34793	0,30328	0,39731	184
2	Hairy cell leukaemia	0,12768	0,10124	0,15891	23
2	Plasmacytoma/Multiple Myeloma (and Heavy chain diseases)	2,07962	1,96822	2,19568	492
2	Mantle cell lymphoma	0,14205	0,11407	0,17480	48
2	Prolymphocytic leukaemia, B cell	0,00958	0,00351	0,02084	4
1	**ACUTE MYELOID LEUKEMIA AND RELATED PRECURSOR NEOPLASMS**	1,84341	1,73861	1,95286	316
2	Acute promyelocytic leukemia (AML) with t(15;17) with variants	0,03192	0,01950	0,04930	9
2	Acute myeloid leukemia	1,46355	1,37035	1,56143	291
1	**MYELOPROLIFERATIVE NEOPLASMS**	2,47064	2,34908	2,59686	277
2	Chronic myeloid leukemia	1,38375	1,29316	1,47901	92

2	Other myeloproliferative neoplasms	1,08689	1,00678	1,17168	183
2	Mast cell tumour	0,00000	0,00000	0,00589	2
1	**MYELODYSPLASTIC SYNDROME AND MYELODYSPLASTIC/MYELOPROLIFERATIVE DISEASES**	0,29367	0,25277	0,33930	210
2	Myelodysplastic syndrome with 5q syndrome	0,00000	0,00000	0,00589	1
2	Other myelodysplastic syndrome	0,27930	0,23945	0,32389	181
2	Chronic Myelomonocytic leukemia	0,01436	0,00657	0,02727	25
2	Atypical chronic myeloid leukemia BCR/ABL negative	0,00000	0,00000	0,00589	1
1	**HISTIOCYTIC AND DENDRITIC CELL NEOPLASMS**	0,05746	0,04024	0,07954	4
2	Histiocytic malignancies	0,05586	0,03891	0,07769	3
2	Lymph node accessory cell tumors	0,00160	0,00004	0,00889	1

Appendix 4: Quality indicators and outcomes for two chosen rare cancers in Bulgaria: soft tissue sarcoma and head and neck cancers.

Soft tissue sarcoma:

Criteria	Quality indicator	Findings from the high resolution study in Bulgaria
Diagnostic management	Percentage of patients with sarcoma undergoing preoperative scan and biopsy before treatment (MRI and/or CT locally and lung CT)	70%
	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)	11% had second opinion (however there was no relevant definition for an "expert pathologist" in Bulgaria for the primary indicator).
Adherence to clinical guidelines	Percentage of patients with low grade and R0 resection margin undergoing surgery alone.	80.7%
	Percentage of patients with high grade and R0 resection undergoing surgical intervention and radiotherapy or radiotherapy and chemotherapy.	20%
	Percentage of patients with R1 or R2 resection margin undergoing surgical re-intervention or, radiotherapy, or chemotherapy and radiotherapy.	31%
Quality of surgery and radiotherapy	Complete tumour resection of definitive surgery	65%
	Reoperation after primary definitive surgery	2%
Quality of pathology report after surgery	Percentage of pathology reports with a full set of core data items recorded according to the ESMO guidelines	12%
Availability of formalised multidisciplinary decision making and care	No indicators	No indicators collected by high resolution study because the information was not retrievable.
Participation in clinical and translational research	No indicators	No indicators collected by high resolution study because the information was not retrievable.

Head and neck:

Criteria	Quality indicator	Findings from the high resolution study in Bulgaria
Timely start of treatment	Time to start treatment (time between definitive diagnosis by a pathologist and beginning of surgery or radiotherapy)	For 80% of the patients the time is less than 4 weeks

	Time in starting postoperative radiotherapy or concomitant chemo-radiotherapy (adjuvant treatments)	For 66% of the patients the time is less than 8 weeks
Stage at diagnosis	Definition of stage at diagnosis	18.6% with Unknown stage
Adherence to clinical guidelines	Percentage of patients with early stage I and II referred for either surgery or radiotherapy	52.7%
	Percentage of patients with locally advanced stage III and IV referred for surgery plus postoperative radiotherapy or postoperative chemo-radiotherapy	52.8%. However, a large proportion of the information regarding radiotherapy in this cohort was missing, and so this may not be representative.
Quality of surgery and radiotherapy	Complete tumour resection (histological verification of tumour free margins after surgery)	20%
	Readmission, reoperation within 30 days from main surgery	No indicators collected by high resolution study because the information was not retrievable.
	grade 3 or more late toxicities (more than 3 months after radiotherapy)	No indicators collected by high resolution study because the information was not retrievable
	Percentage of patients receiving intensity-modulated radiation therapy vs receiving 3D conformal radiation therapy	No indicators collected by high resolution study because the information was not retrievable
	Availability of all types of surgery and reconstructive surgery	No indicators collected by high resolution study because the information was not retrievable
Quality of pathology report after surgery	Percentage of pathology reports with a full set of core data items recorded according to the ESMO guidelines	20%
Availability of formalised multidisciplinary decision making and care	No indicators	No indicators collected by high resolution study because the information was not retrievable
Participation in clinical and translational research	No indicators	No indicators collected by high resolution study because the information was not retrievable

Appendix 5: The number of treatment centres identified for rare cancers in Bulgaria.

Cancer type	Number of centres
Head and Neck	49
Central Nervous System	14
Neuroendocrine Tumours	21
Endocrine Tumours	28
Sarcomas	47
Haematological Tumours	21
Male Genital Organs	16
Childhood cancers	7
Female Genital Organs	27
Digestive Cancers	12
Malignant Mesothelioma	13

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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