RARECARENet
Information Network on Rare Cancers

INFORMATION NETWORK ON RARE CANCERS (RARECARENET)

Duration in months: 36 months (starting date 1st May 2012)

EXECUTIVE SUMMARY

Objectives
The project aims at building an information network to provide comprehensive information on rare cancers to the community at large (oncologists, general practitioners, researchers, health authorities, patients). The final objectives are to improve the timeliness and accuracy of diagnosis, to facilitate the access to high quality treatment for patients with rare cancers, to identify centres of expertise for rare cancers in Europe and to standardize practices across Member States (MS).

Strategic relevance & contribution to the programme
Rare diseases including rare cancers are a priority for action in the Public Health Programme (2008-2013). The importance of providing accurate information on rare diseases to all European citizens is clearly stated in the Communication of the European Commission "Rare Diseases: Europe's challenge" and in the Recommendations from the Council. This project will closely collaborate with the European Partnership for Action Against Cancer (EPAAC). Thus, in accordance with the Second Health Programme (SHP) and Annual Work Plan, it will contribute to health protection and safety of citizens through actions in the field of cancer. It will help to identify the causes of inequalities in the area of rare cancers, monitoring incidence, survival and prevalence, within the EU and to exchange the best practices to tackle them. The proposed network will increase the existing information about rare cancers and will support a practical use of the information produced in different European countries.

Methods and means
Information on the hospital of treatment will be collected by cancer registries (CRs) in a subset of countries. The association between outcome and hospital case volume will be analyzed. The criteria to identify centres of expertise for rare cancers, in accordance with the European Reference Network on all rare diseases, will be defined by a specific working group including all concerned stakeholders. For a subset of rare cancers, the criteria identified will be tested collecting relevant information in collaboration with CRs. From the identified criteria, a list of centres of expertise will be developed by the European Cancer Patient Coalition (ECPC) conducting a survey among members. Experts will be invited to revise the list of rare cancers. Updated incidence, prevalence and survival figures for Europe will be provided using the most recent EUROCARE database. Information on diagnosis and treatment of rare cancers will be developed by the project State-of-the-Art Oncology in Europe (START).New knowledge on very rare cancers will be produced developing a prospective clinical database.

Expected Outcomes
The proposed network is expected to contribute to:

- promote better classification of rare cancers complementing the EU dynamic inventory of rare diseases developed by the portal for rare disease Orphanet
- produce and disseminate information material about rare cancers building a knowledge system involving all concerned stakeholders
- ameliorate diagnosis, treatment and referral of patients with rare cancers to appropriate centres of expertise
- promote international collaborative groups to foster research on very rare cancers
- identify determinants of variations in survival across Europe and develop recommendations to improve the situation reducing health inequalities across Europe
- support better health care planning and resource allocation for rare cancers
- empower patients

PROBLEM ANALYSIS INCLUDING EVIDENCE BASE

The project Surveillance of Rare Cancers in Europe (RARECARE) estimated the burden of rare cancers in Europe providing the first indication of the size of the public health problem due to these diseases and constituting a useful base for implementing public health actions and for further research. According to RARECARE, around 4 million people in the European Union (EU) are affected by rare cancers. Despite the rarity of each of the 186 identified rare cancers, they represent all together about 22% of all cancer cases diagnosed in the EU27 each year. Five-year relative survival is significantly worse for rare cancers (47%) than for common cancers (65%) (www.rarecare.eu) and differences in survival exist across European regions (Gatta G. Lancet Oncology 2006). There is general agreement that treatment of rare cancers should be concentrated in specialist multidisciplinary centers, and that international collaboration is needed to undertake research in this group of patients. However there is no evidence on the impact of such initiatives on survival. Due to their low frequency, rare cancers pose particular challenges such as: late or incorrect diagnosis, lack of access to appropriate therapies and clinical expertise, limited information about them and a dearth of clinical trials. In responses to these challenges, the Rare Cancers Europe (RCE) has launched the Call to Action that urges policy-makers and stakeholders to give priority to rare cancers. In particular it is campaigning to: 1) foster the creation of reference networks for the treatment of patients with rare cancers, 2) spread knowledge and clinical guidelines on rare cancers, 3) promote the establishment of clinical databases and registries and 4) empower patients. Against the background described, a key goal is to build on a network of cooperating organizations collaborating in research, promotion and implementation of appropriate solutions to address rare cancers challenges.

GENERAL OBJECTIVES

The proposed project aims at building an information network to provide comprehensive information on rare cancers to the community at large (oncologists, general practitioners, researchers, health authorities, patients and their families). Such information will contribute to a more effective organization of health care services for rare cancer patients in order to improve the timeliness and accuracy of diagnosis, to facilitate the access to high quality treatment, to identify centers of expertise in Europe and to standardize practices across Member States (MS).

SPECIFIC OBJECTIVES

No	Title	Description
1	To collect and disseminate information on the health care pathways for rare cancers and on updated epidemiological indicators.	Data on hospital of treatment and diagnosis will be collected from cancer registries to describe the health care pathway for rare cancers in EU. Updated epidemiology indicators, incidence and survival trends will be provided for rare cancers in EU.
2	To identify the qualification criteria for centers of expertise for rare cancers.	Following the criteria for European Reference Network for rare diseases, a list of qualification criteria will be developed in collaboration with major scientific societies and the European Cancer Patient Coalition (ECPC).
3	To identify and disseminate information on centers of expertise for rare cancers.	ECPC liaising with the Rare Cancers Europe(RCE)will build on the qualification criteria for centers of expertise previously identified and will ensure the engagement of patients to identify centers of expertise for rare cancers.
4	To produce and disseminate information on diagnosis and management of rare cancers.	Work will be undertaken by the project "State of the Art - Oncology in Europe" (which involves experts of oncologic societies)in collaboration with the RCE and the European Partnerships for Action Against Cancer (EPAAC).
5	To develop a clinical database on very rare cancers to provide new knowledge on these diseases and on their clinical management.	An online, prospective clinical database will be developed to pool clinical cases of very rare cancers from different EU countries. On the basis of the information collected, the best way to take care of these patients will be defined.
6	To develop and disseminate information for patients including a list of patients' associations dedicated to rare cancers.	Together with the partners, the ECPC (liaising with the RCE) will produce information material on rare cancers for the patient community and for the general public. Patients' associations dedicated to rare cancers will be identified too.

METHODS AND MEANS

A subset of participating cancer registries (CRs), selected for wide national coverage and for European representativeness of different social, cultural and political context, will send individual data including information on the hospital of treatment for all incident cases. For all rare cancers, hospitals in which patients are most frequently treated will be detected. Referral and treatment pathways of patients will be analyzed. Association between outcome and hospital case volumes will be investigated. Confidentiality problems regarding both patients and individual hospitals will be considered by shaping the published output according to the local legislation. A meeting with experts will be organized to update the list of rare cancers. Updated incidence, prevalence and survival figures for Europe will be provided with the methods already used in the previous RARECARE project and using the most recent Survival of Cancer Patient in Europe (EUROCARE-5) database. The criteria to identify the centers of expertise for rare cancers, in accordance with the European Reference Network on all rare diseases, will be discussed and defined within a working group including major oncologic societies and patients organizations. For a subset of rare cancers, the criteria identified will be tested by using the treatment volumes data already available to the project and collecting other relevant information in collaboration with CRs (high resolution studies). This information will be analyzed and discussed with different stakeholders to reach a consensus on the qualification criteria for centers of expertise for rare cancers. From the identified criteria, a list of centers of expertise will be developed by the European Cancer Patient Coalition (ECPC) (liaising with RCE) conducting a survey among members. A knowledge system will be built to produce information material explaining rare cancers to the patient community and to the general public by different means: website, twitter account, newsletters and events. Rare cancers patients' associations will be identified and involved in the activities. The proposed network will collaborate with the project state-of-the-art oncology in Europe (START) in order to provide information on rare cancers management . START is intended as a decision support tool for oncologists, functioning and internationally recognised since 2004. START is evidence-based, but also descriptive and critical of available options on diagnosis and treatment, to encourage an individualized clinical decision making at the patient's bedside. Thus, START will provide information on specific rare cancers regarding diagnosis, treatment and follow-up to support clinical oncologists and physicians in their everyday oncology practice. Each chapter will be drafted by European experts under the supervision of an internal editor and submitted to reviewers. All the experts and institution participating to the preparation will be enlisted in the website. An online clinical database will be developed to collect cases of very rare cancers. In collaboration with existing networks of centers/researchers, a subset of very rare cancers and a related common dataset will be selected. Oncologist dealing with such very rare cases will use, with a private access, the website to input and share information on the treatment and related response of their patients.

EXPECTED OUTCOMES

The overall outcome is to serve as the reference source of information on rare cancers in Europe contributing to ameliorate diagnosis and treatment of rare cancers, to foster research on rare cancers, to support the establishment of centers of expertise and to empower patients. The list of rare cancers continuously updated and published will promote better classification of rare cancers. The list will complement the EU dynamic inventory of rare diseases developed by Orphanet providing information on rare cancers and contributing to identify which cancers are rare. Information on health care pathways and estimates of survival differences by European region will contribute to identify determinants of variations in survival across Europe and to develop recommendations to improve the situation reducing health inequalities across Europe. Updated incidence and prevalence data will support better healthcare planning and resource allocation for rare cancers. The availability of prevalence data updated to 2007 for rare cancers will also facilitate application of the EU orphan drug directive. Monitoring time trends of rare cancers will improve information for health care planning, from primary prevention to care. The availability of criteria for centers of expertise for rare cancers will be essential to identify them, to establish networks of such centers in Europe and harmonize practices across EU countries. Networks of reference centers are essential to increase knowledge on rare cancers, define and share best practice, put expert knowledge at disposal of physicians, improve overall rare cancers diagnosis, treatment and research. Knowledge of the centers at which rare cancer patients are most frequently referred to will help patients and their GPs in finding an appropriate hospital for treatment. Information on diagnosis and treatment of rare cancers will support clinical oncologists and physicians in their everyday oncology practice. This will contribute to ameliorate the timeliness and the appropriateness of diagnoses as well as the overall diseases management. The clinical database will support the pooling of cases of very rare cancers leading to the development of new knowledge and to the definition of a more homogeneous clinical management of such rare diseases. It will also contribute to the development of international collaborative groups to foster research on rare cancers. Empowerment of rare cancer patients needs information and education. The

network will contribute to inform, educate and motivate patients. Information will flow, not only to them but also from them, so that their needs can be known and they will be finally able to take responsibility, understand their own disease and who could take care of it. In general they might better participate in the shaping of the health agenda and become empowered patients. The outcomes described will all contribute to ameliorate survival of patients with rare cancers.

WORK PACKAGES

Title	Description
Information on epidemiology of rare cancers	This WP will develop information on the health care pathway of patients with rare cancers and will update the epidemiological indicators for all rare cancers of the RARECARE list
Information on centres of expertise for rare cancers	This WP will identify, with a wide consensus process and high resolution studies, the qualification criteria for centres of expertise for rare cancers
Information on clinical management of rare cancers	This WP will develop information on diagnosis and treatment for a selected number of rare cancers and will develop new information on very rare cancers
Information for patients with rare cancers	This WP will produce information about rare cancers (including patients organizations dedicated to rare cancers, list of centres of expertise, etc)in formats adapted to patients need
Coordination of the project	Actions undertaken to manage the project and to make sure that it is implemented as planned
Dissemination of the project	Actions undertaken to ensure that the results and deliverables of the project will be made available to the target groups
Evaluation of the project	Actions undertaken to verify if the project is being implemented as planned and reaches the objectives

WORK PACKAGES - DESCRIPTION OF THE WORK

WP Information on epidemiology of rare cancers

Objective
To collect and disseminate information on the health care pathways for rare cancers and on updated epidemiological indicators.

Methods
Many CRs systematically collect information on the hospital of diagnosis and/or treatment. A subset of participating registries, selected for complete national or regional coverage and for representing different European geographical areas will send individual data with this information for all incident cases. These registries are the national registries of Finland, Ireland, Bulgaria, Slovenia and Netherlands. Other registries can join at a later stage. Registries invited to participate belong to different cultural and socio-economic context. This is important because it will ensure that information collected will be representative of different background within the EU. Availability of the place of treatment for all rare cancer patients will allow to detect in which hospitals they are most frequently treated, to analyze their referral and treatment pathways, and to investigate on possible association between outcome and hospital case volumes. The availability of such information per country and/or per different socio-economic situation will allow to study and better understand the impact of the context on outcome (survival) and therefore to provide recommendations taking into account the differences existing among MS. Possible confidentiality problems, regarding both patients and individual hospitals, will be addressed by shaping the published output according to the local legislation.

Revision of the list of rare cancers: as any standard classification of tumors, also the list of rare cancers (which derives from the ICD-O) need continuous revision and updates. A consensus meeting is envisioned to convene the group of international experts and oncologic societies to revise the list.

Epidemiological indicators: the new EUROCARE/RARECARE database, which includes all the incident cases in 1978-2007 from more than 100 CRs from 30 Countries, will be used. The new database includes several Eastern and Southern European Countries: Bulgaria, Croatia, Estonia, Hungary, Latvia, Lithuania, Slovakia. This will allow to provide indicators for new EU member states. The new database also includes a longer period of diagnosis (2000-2007) in which cases have been consistently reported with the most recent classification system. This will allow to analyze time trends and to provide more robust indicator estimates. Analyses will focus on the updated list of rare cancer. Incidence, prevalence, and absolute and relative survival will be estimated by the same methods used in the previous RARECARE project. Joint Point method will be used for incidence trend analysis. Survival time trends will be estimated using multiple regression models

Deliverables

- Report on the health care pathway study and on the updated epidemiological indicators

WP Information on centers of expertise for rare cancers

Objective
To identify the qualification criteria for centers of expertise for rare cancers

Methods
In accordance with the general criteria for European Reference Network on all rare diseases a list of criteria indicating the level/quality of expertise for rare cancers management will be developed in collaboration with multidisciplinary experts of the major scientific societies (ECCO, ESTRO, ESSO, ESMO) patient organizations (ECPC), and policy makers representative of new MS and countries with different cultural, social and political background. Possible criteria could be: 1) the attractiveness measured through the volume of cases treated (including referral pattern), 2) the capacity to produce and adhere to clinical guidelines (i.e. staging procedure and treatment), 3) outcomes (i.e. number of revision surgery, survival and recurrence), 4) the availability of multidisciplinary team, 5) the collaboration with other centers of expertise at national and international level (also for clinical trials). For a selected sub set of rare cancers, more specific indicators will be identified together with the clinicians and the ECPC (liaising with RCE) and will be collected through high resolution studies in a sub-set of countries with different socio-economic context. In addition to the CRs that are already partners of the project, additional CRs will be subcontracted to enlarge the data collection. Cancer registries do not routinely collect clinical information, in consequence cancer registries will be requested to check again the clinical files to collect clinical information on staging procedures, treatment, recurrence, multidisciplinary teams etc. These type of studies (high resolution studies) are new for rare cancers. A meeting will be organized to discuss possible criteria indicating the level/quality of expertise for rare cancers management. During this meeting the subset of cancers on which the high resolution study will be undertaken, will be selected. Small tumor specific groups will be created to discuss specific indicators for the sub set of cancers identified and to develop the protocol for the high resolution study. The information collected will be analyzed and discussed with clinicians, patients, scientific societies, and health authorities coming from different MS including the new EU MS.
The results of this exercise will be presented at the EUCERD meeting where representatives of many and different MS are represented and will be able to provide comments according to their own country experience and context.

Deliverables

- Report identifying criteria indicating the level/quality of expertise for rare cancers management

WP Information on clinical management of rare cancers

Objectives
To produce and disseminate information on diagnosis and management of rare cancers
To develop a clinical database on very rare cancers to provide new knowledge on these diseases and on their clinical management.

Methods
Information on clinical management on rare cancers to support clinical oncologists and physicians in their everyday oncology practice will be developed in collaboration with the project State-of-the-Art Oncology in Europe (START)

which involve experts of major oncologic societies. START will be subcontracted to produce the chapters on rare cancers. Each START chapter results from a definite, internal collaborative process. A draft version is assembled by one of the START Editors on the basis of selected contributions from Authors. One or more European experts in the field then act as internal reviewers for the chapter. The chapter is put online, a laymen's version of the main content is developed and all the people taking part into its preparation are enlisted. Major oncologic societies (ESSO, ESTRO, ESMO) will be contacted to explore their interest in developing clinical information on rare cancers different from those developed by START.

Clinical database. A clinical database will be developed to collect cases of very rare cancers (incidence < 0,01/100,000/year). Only a European database will allow to collect a sufficient number of cases to study the natural history of the disease and to define possible clinical practice. The database will be developed in collaboration with already existing networks of centers/researchers (French observatory for rare malignant tumors of the ovary, collaboration group on nasopharyngeal cancers). A meeting is envisioned to discuss about the database and to select a subset of very rare cancers for which define the database. The selection will be based on the very rare cancers cases available in the EUROCARE/RARECARE database. A working group will be established to identify a common minimum dataset on the selected very rare cancers and to oversee the development of the database. The database will be available on the web-site but will be restricted to physicians only. All members of the networks involved will be informed about the database and will be invited to include cases.

Deliverables

- START chapters on rare cancers
- Database on very rare cancers

WP Information for patients with rare cancers

Objectives

To identify and disseminate information on centers of expertise for rare cancers.

To develop and disseminate information for patients including a list of patients' associations dedicated to rare cancers.

Methods

In order to empower rare cancer patients one needs patient education. Together with the partners, the ECPC (liaising with RCE) will build a knowledge system and will produce information material explaining rare cancer, treatment and, following input and guidance, explain outcomes to the patient community and to the general public. In order to reach a large number of patients, ECPC would use a multiplier communication model involving well linked rare cancer advocates and membership organizations who would be the multipliers disseminating the information to rare cancer patients.

Based on the information material developed in collaboration with the project partners, ECPC (liaising with RCE) would organize at least 4 workshops to train the patients advocates to inform, educate and activate other rare cancer patients (Train the trainers approach). This workshops will target patients coming from EU countries with different socio, cultural and political background and will take place in different countries (including countries that do not have extensive expertise in rare cancers). This will allow to train patients and discuss with them whether the materials developed are adequate for their country context. Such discussion will help also to identify the best communication channel in different socio-cultural context. Additional communication channels might include web site, twitter account, newsletters and events. With the help of the established multiplier patient network it will be easier to reach significant number of patients for a substantiated survey identifying clinical centers of expertise. The questionnaire for this survey will be developed in a joint working group formed by the work package partners and will build on the qualification criteria for centers of expertise identified by the WP5. The results of the questionnaire will be discussed during the workshops that will be organized with patients. Such workshops will constitute a major strength to understand to what extend the qualification criteria proposed for centres of expertise are suitable for different context and to discuss the transferability of the recommendations on center of expertise in different countries/background. ECPC has worked with a network of around 300 organizations across EU 27 over the last 10 years and many of these are members the ECPC Rare Cancer Action Group. The established multiplier patient network will contribute to identify additional patients associations. All communication will be multilingual in order to

reach the most European rare cancer patients possible and to receive a presentable feedback concerning the clinical centers of expertise. The printing of the information and the development of the web-site will be subcontracted.

Deliverables

- Informative materials for patients
- List of centers of expertise for rare cancers

WP Coordination of the project

The INT (Evaluative Epidemiology unit) is the coordinator. The coordinator is responsible for undertaking all necessary measures to ensure the achievement of the objectives of the network. The Coordinator is the link with the European Commission. The Coordinator will report on the activities and finances and will provide feedback to the Steering Committee (SC) on information coming out from the Commission, from other successful projects and from the EUCERD of which the coordinator is a member. The coordinator is supported by the project management team (PMT) to fulfill these tasks. The work of the PMT will include the following tasks:

- Development of the project management section of the web-site
- Development of instruments for the project management (Document Management System, Project Management Tool) .
- Preparation of SC meetings.
- Preparation of progress reports and monitoring the delivery of milestones. The PMT will ask to each WP leader to complete a WP report each 6 months after the start of the WP. The WP report will contain, for each task the following elements: objectives (as a memorandum); work done and encountered problems with possible causes; produced documents (to be enclosed); next steps and proposals with possible problems / risks.

The PMT will be responsible of overseeing the financial and administrative management of the project. The team will ask to WP leaders to develop a brief financial report before the second and third SC meetings at month 23 and at month 32. The report will include information on money spent, problems incurred in spending the money, plan of expenditure for the next 12 months (the latter only for the first report). This will allow to monitoring whether money are spent on time by each partners. A summary of the financial situation will be presented during the SC meetings in order to discuss possible problems raised and to agree on necessary budget changes within one partners and/or among partners. The results of the discussion will form the basis for the development of the interim and final financial report.

During the first SC meeting, the financial rules will be explained to partners and will be discussed with them how the funds will be distributed following the EAHC rules.

The PMT will provide economic and administrative support to the WP Leaders since the beginning of the project including explanation of the budget, eligible costs, development of the brief financial report. The management team will monitor the correctness and accuracy of financial reports developed by partners, will collect the cost statements, and will support the coordinator in developing the financial reports required.

The SC will consist of one representative from each different associated partner of the project. The SC will be the decision making body. The SC will be responsible for all strategic planning, ensuring that the timetable is maintained and that the milestones are met and that corrective actions will be taken if necessary. It will receive all reports and other outputs for quality control. It will have to decide on other future actions which will be taken cooperatively. Three meetings of the SC are envisaged.

The START director which is the WP6 leader of the proposed network is a medical oncologist, with special expertise in head and neck cancers. She will be involved in the SC meetings considering her clinical expertise on rare cancers, useful in all the different activities of the project, and her specific tasks related to START. During the SC meetings she will be asked, as all other WP leaders, to report about the progresses and possible problems in the development of the chapters about the clinical management of rare cancers.

Coordination and collaboration with other initiatives in EU

The EPAAC has a work package on health care which aims also to *promote harmonization of Clinical Guidelines focused on rare cancers.* The Coordinator of the proposed network is a partner of this WP and will ensure a collaboration among the two initiatives. Actually the EPAAC WP7 is planning to organise a workshop with organisations/scientific societies developing clinical guidelines to review current clinical practice and explore agreements and discrepancies. The coordinator of the proposed network and the director of START (involved in the proposed network) will participate to the workshop and the conclusions will be considered in developing the START chapters dedicated to rare cancers.

The proposed network will collect information on patients associations and will share the list of patients associations dedicated to rare cancers with the EPAAC WP since they were interested in this information too.

The RCE is a multi-stakeholder initiative dedicated to putting rare cancers firmly on the European policy agenda and to implementing 39 political and stakeholder recommendations. The proposed network will contribute to the implementation of some of this recommendations coordinating its activities with the RCE which, intentionally was invited to be a collaborating partners of the project. The proposed project will provide the updated estimates of the rare cancers burden and will assess the impact of the implementation of the RCE recommendations in terms of survival of patients with rare cancers. Nobody else, within the RCE consortium is providing such estimates.

The proposed network will collaborate with Orphanet to update the inventory of rare diseases and to provide information on rare cancers. Orphanet is a collaborating partners of the project thus discussion will be held to ensure that the results and information on rare cancers will be included without overlapping also in Orphanet.

The proposed network will develop a list of centers of expertise and a list of patients associations dedicated to rare cancers in collaboration with ECPC and its Rare Cancers Action Group. The present project will be an opportunity for the ECPC to identify additional patients associations and to provide information to patients developed in collaboration with experts of the proposed network. Thus, again the proposed network will ensure collaboration among the different organizations working on rare cancers in Europe.

Finally, the proposed network will collaborate with the EUCERD joint action and in detail with the WP7 (mapping national initiatives addressing the quality of care in the field of rare diseases) and the WP8 (integration of rare diseases initiatives across disease specific and national areas).

WP Dissemination of the project

The proposed network will produce and disseminate information on:

- the burden (incidence, prevalence, survival and trends of incidence and survival) of rare cancers
- the qualification criteria of centers of expertise for rare cancers
- the list of centers of expertise for rare cancers
- the clinical management of rare cancers (collaborating with START)
- general information about rare cancers for patients

The key message for policy makers and health authorities will be that rare cancers are a problem considering their burden in the population and the challenges in research and clinical management. Possible solutions according to the RCE recommendations will be also suggested.

The message for health care professionals will be about the importance of a timely diagnosis and proper referral to centres of expertise for rare cancers (the list of centers of expertise will be developed and disseminated to support the appropriate referral of patients).

For specialist, the message will be the availability of guidelines including evidence based options on diagnosis and treatment of rare cancers. Another key message is the availability of a database, to collect information on very rare cancers cases, to which they should contribute when possible.

For patients the messages will be the availability of centres of expertise, the availability of patients associations they can get in contact with, the importance and challenges of rare cancers and what can be done to overcome such obstacles.

Information developed will be disseminated through:

- The RARECARE web-site will become a web-based which will have dedicated areas on specific topics (guidelines and information on rare cancers, centers of excellences, patient organization, epidemiological data). Linkages will be established with the EUCERD, EPAAC, RCE, START, ESO and ECPC web-sites
- Publication in major public health and clinical journals and presentation at conferences
- Reports at the meetings of the EUCERD
- Major newsletters (OrphaNews Europe, ECPC newsletter),
- European Parliament Cancer Patient Interest Group (for example, Forum Against Cancer in Europe - FACE) have a proven track record of tackling the key policy issues and sensitizing policy makers to recognize the unmet needs of rare cancer patients in Europe and the need to tackle rare cancers through regulatory means
- ESO educational instruments (conferences, training courses in native language, online meetings)
- Policy brief
- EPAAC open forum

Information will be developed in formats adapted to the needs of professionals and of patient groups; patient information will be multilingual. START will develop information on the clinical management of selected rare cancers and will release the information developed on the proposed network and on the START website.

Dissemination means by target group

- Oncologists and general practitioners: proposed network and START web-site. RSS feed will ensure readers who subscribe to get timely updates from the network web-site. Presentations at conferences and publications. In collaboration with the ESO innovative approaches will be developed to increase awareness about rare cancers
- Researchers: proposed network web-site, presentations at conferences, publications, newsletter
- Health authorities: policy brief, reports at meetings of the EUCERD & EPAAC, FACE, cancer week and rare diseases day celebration
- Patients: proposed network web-site, newsletter, ECPC events & workshops

The EU co-funding will be indicated on the web-site of the project, on the informative materials that will be produced for patients, on the slides developed for presentations at congresses and in the articles that will be published. The EU logo and clarification about the EU co-funding will be also included on START web-site and in each START chapters that will be developed, with the funds of the proposed network, on rare cancers.

WP Evaluation of the project

The evaluation modalities envisaged follow:

- **Process Evaluation** – to provide data during the project in order to allow making mid-course decisions to ensure successful results (is the project being conducted as planned?);
- **Product Evaluation** – is aimed at understanding if stated goals and objectives have been met; outputs, results, documents and products will be evaluated;

The **process evaluation** will allow project decision bodies (the PMT and the SC) to understand if the project objectives are met, if the due dates can be respected, if resources are enough for envisaged activities, if external situations require changes in the project objectives.

Typical decisions that could be taken based on the process evaluation are:

- Is it necessary to re-negotiate project objectives with the EAHC?
- Is it necessary to re-negotiate project plans with their dead lines with the EAHC?
- Is it necessary to search for additional resources?

PMT will ask to each WP leader to complete a WP report each 6 months after the start of the WP. The WP progress report will contain, for each task the following elements:

- Objectives (as a memorandum);
- Work done and encountered problems with possible causes;
- Produced documents (to be enclosed);
- Next steps and proposals with possible problems / risks.

Evaluators
An internal evaluation will be performed by the PMT (including the coordinator) under the responsibility of the WP3 leader and with the general coordination of the SC.

In addition, an external evaluation, will be asked to an Advisory Board (AB). The WP3 leader will propose two experts external to the network to constitute the AB. The AB will assess whether actions taken by the network are coherent with its objectives, and are undertaken as planned. During its first meeting, the AB will examine the list of indicators developed by the project and will modify this list if necessary.

The **product evaluation** will focus on the following products:

- Project leaflet;
- Informative materials for patients;
- Report on the health care pathway study and on the updated epidemiological indicators;
- START chapters on rare cancers;
- Database on very rare cancers;
- Report identifying criteria indicating the level/quality of expertise for rare cancers management
- List of centers of expertise for rare cancers .

The following criteria will be considered:

- Exposure clearness;
- Soundness of concepts;
- Scientific relevance and potential impact on intended targets;
- Ease of use.

Evaluators
The PMT and the SC will provide comments during the preparation of the documents produced (internal evaluation). The AB will review the documents produced and will discuss them with the coordinator during the AB meetings. Three meetings of the AB are envisioned: the first within one year from the start of the project, the second after 2 years and the third before the end of the project.

In case of very poor evaluations of project products by the AB, the SC will evaluate the possibility to envisage additional work to refine the documents. This could lead to a change in the project plans that will be prepared by the project management team and, in case of big changes, approved by the EAHC.