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Outputs

Report on consensus/recommendations on the key criteria used for the organisation, governance and harmonization of rare cancer care policies at national and the EU level

JARC evaluation report

Lay version of the final report

Report of the Final JARC conference

Recommendations on how to exploit CRs data for research and for the development and assessment of future ERNs

Report summarising the results of the survey on accessibility of standard treatment and recommendations to Member States and Europe to overcome bottlenecks

Report summarising recommendations to facilitate referral of children to trial centers offering innovative medicines

Report summarising proposals to address extremely rare cancers in young patients

Guidelines and recommendations on models of healthcare to assure adequate follow-up of children surviving cancer, transition to adult medicine, and the use of a Survivorship Passport

Report on policy and organisational issues affecting the development of ERNs

Report on orphan drug designation and marketing authorization process for medicinal products for rare cancers

Definition of a model for linking clinical and population based CR data

A framework of systems-based quality standards applicable to all networks and centres for rare cancers adding to ERN requirements

Recommendations on optimal implementation of clinical practice guidelines on rare cancers

Report summarizing the status of the development of UEMS-EU harmonized educational principles and recommended training materials for rare cancers

Recommendations to improve the quality of rare-cancer registration in population based CRs

A proposal for quality assurance processes specific to rare cancers and consistent with ERN requirements focusing on improving quality of care, based on peer review and patient involvement

Recommendations on how to integrate clinical practice guidelines into existing healthcare networks, with special reference to ERNs

Recommendations on requirements for long-term surveillance of rare cancer patients (for each family of rare cancers)

Roadmap on precision medicine in rare cancer care within ERNs

Report on development of educational tools and learning programmes for the rare-cancer patient communities

Recommendations for the standardized estimation of rare cancers indicators at the European and country level

Map/Database of expert centres and networks on rare cancers in Europe

Report on the assessment of the quality of existing clinical practice guidelines (for each family of rare cancers)

Report on QA/QC guidance for collection of biological samples and data on rare cancers in the EU

Map of available continuous medical education resources on the 12 families of rare cancers and recommendations on their integration within ERNs

List of existing preclinical paediatric cancer models and skilled research teams involved in preclinical research
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## Joint Action on Rare Cancers

### JA2015 - GPSD [705038]

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<td><strong>CALL:</strong></td>
<td>Health Programme Adhoc Call for invited (named) beneficiaries</td>
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<td>Rare cancer</td>
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<td>Rare diseases</td>
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Project abstract

This Joint Action on Rare Cancers (JARC) will be aimed at:

1. prioritising rare cancers (RCs) in the agenda of the Europe (EU) and Member States;
2. developing innovative and shared solutions for European Reference Networks (ERNs) on RCs, in the areas of quality of care, innovation, education and state of the art definition on prevention, diagnosis and treatment.

The objectives of JARC will be achieved by creating a platform for competent national authorities as well as institutions, scientific and professional societies and patient organisations, to produce consensus-based recommendations, with a special view to the new ERNs, seen as a great opportunity for improvement of RC patient outcomes in the EU.

Following the results of the RARECARE project, all the 12 families of RCs will be considered. Consensus-based recommendations about RCs will be provided to improve: 1) epidemiological surveillance of RCs; 2) quality of healthcare, primarily through the new ERNs; 3) the availability of clinical practice guidelines on RCs; 4) innovation, also by optimizing clinical research regulations as well as practices and semantics regarding patient data and tissues; 5) medical and patient education; 6) health policy measures on RCs at the EU and national level; 7) patient empowerment (which will be pursued across all items dealt with by JARC). All EU stakeholders in the field of RCs and rare diseases will be involved.

JARC will carry forward the aims of the Third Health Programme by improving chances of EU RC patients to have access to appropriate healthcare, primarily through optimal shaping of ERNs. Thus, all this should result in reduced healthcare inequalities, increased innovation in health, increased sustainability of health systems, decreased health migration and reduction of gaps in rare cancers survival across EU countries.

Summary of context, overall objectives, strategic, relevance and contribution of the action

The Joint Action on Rare Cancers (JARC) is aimed to integrate and maximize efforts of the European Union (EU) Commission, EU Member States and all stakeholders to advance quality of care and research on rare cancers (RCs). According to the results of the RARECARE project, around 4 million people in the EU are affected by RCs. There about 200 different rare cancers which can be grouped in the following major families: head and neck cancers, thoracic rare cancers, male genital and urogenital rare cancers, female genital rare cancers, neuroendocrine tumours, tumours of the endocrine organs, central nervous system tumours, digestive rare cancers, rare skin cancers including uveal melanoma, haematological rare malignancies, all paediatric cancers.
The public health challenge posed by rare cancers combines both the typical problems of rare diseases (such as the limited professional expertise multidisciplinary in the community, or the difficulties in clinical research) and those of cancer, with the need of a timely and appropriate diagnosis and optimal treatment from the very beginning of the patient’s journey. An accurate clinical, pathologic and biological assessment of the disease of the individual patient is key to survival and cure, as well as an expert clinical decision provided by a multidisciplinary team. To this end, proper referral of patients and effective clinical networking are crucial in rare cancers. This is the main reason why JARC decided to shape its efforts around the new European Reference Networks (ERNs). European Reference Networks, three of which are specifically devoted to rare cancers, have been conceived by the EU Commission as a means to provide “highly specialised healthcare for rare or low-prevalence complex diseases”. The formal activation of ERNs is a cornerstone in the EU cooperation on rare cancers, and this Joint Action will be instrumental to make them grow up the best way possible.

In fact, JARC aims at optimizing the process of creation of the ERNs, by providing them with performance indicators/criteria operational solutions and professional guidance in the areas of quality of care, epidemiology, research and innovation, education and state of the art definition on prevention, diagnosis and treatment of rare cancers.

The Istituto Nazionale Tumori, with a long tradition on several rare cancers, has the privilege to serve as the coordinator of this EU Joint Action armed with the collaboration of 34 partners from different MS. The Member States involved in the present JA ensure the coverage of all European regions: Western Europe (France, Belgium), Central Europe (Czech Republic, Germany, Hungary), Eastern Europe (Poland, Romania), Northern Europe (Sweden, Finland, Norway, Ireland, United Kingdom, and Lithuania) and Southern Europe (Cyprus, Croatia, Greece, Italy, Spain).

Methods and means

The JARC is structured in 10 work packages (WPs): coordination, dissemination, evaluation (as any EU project), epidemiology, quality of care, clinical practice guidelines, innovation and access to innovation, medical education, childhood cancers and, rare cancers policy. Patients are represented across all work packages, driving the JARC efforts along the needs of the only end users of all what we can do, in care and research as well. The WPs work include reviews of scientific and lay literature on RCs, innovative ways of ad hoc collection and analyses of data pertaining to RCs, discussion with experts. The most important requirement is to seek the widest consensus possible among all relevant stakeholders.
Work performed during the reporting period

Improving epidemiological surveillance of rare cancers in the EU
• A consensus paper about the rationale of the rare cancer list was developed based on a consensus meeting.
• In collaboration with the European Network of Cancer Registries (ENCR), draft recommendations were defined for rare cancers with registration problems and without existing registration guidelines (sarcoma, including gastrointestinal stromal tumour (GIST) and neuroendocrine tumours). A pilot study was performed to assess the feasibility for cancer registries to collect stage for rare cancers taking the example of childhood cancers.
• Recommendations for the standardized estimation of rare cancers indicators at the European and country level were discussed and finalised.

Identifying standards of care for all families of rare cancers to ensure sharing of best practices and equality of care for rare cancers across Europe, particularly through clinical networking
• The existing networks of care for all 11 families of rare adult cancers, across all Member States (MS) were mapped to identify gaps in current scenarios.
• After a literature review on existing care networks, and also an in-depth comparative study of other cancer accreditation standards, a draft of the Quality Standards for Rare Cancer Networks has been achieved with inputs from Partners in the JARC, EURACAN, EURORDIS, ECPC. A first consensus meeting was to discuss the draft with a wider community of experts. The draft was also shared with the ERN Monitoring and Evaluation working group.

Clinical practice guidelines
• A review of clinical practice guidelines (CPG) available at the national and international level on all families of rare cancers and a quality assessment of oncology guidelines identified has been finalised. Out of the 537 guidelines produced 228 full text guidelines were selected for quality evaluation based on the Cluzeau instrument and the binary scored instrument, iCAHE (international Centre for Allied Health Evidence).

Rare cancers translational research landscape
• Recommendations on standardization of clinical data and patient-centred clinical outcomes for big data optimal exploitation and connection to virtual bio banks and quality assurance/quality control (QA/QC) in regard to biological samples, data collection and molecular screening were produced.
• Recommendations to solve regulatory and organisational challenges in conducting international investigator-driven collaborative clinical trials on rare cancers were identified.
Medical education
• Education materials and training opportunities were identified for professionals (6449 review papers; 37 life events; 13 links and 41 books were collected) and for patients in collaboration with EURORDIS, ECPC and CCI Europe.
• A survey to collect information on pre and post-graduate courses dedicated to rare cancers was completed. The survey targeted European Union of Medical Specialists, European Board of Medical Genetics, European Society of Human Genetics and JARC partners.

Childhood cancers
• Availability of standard treatments across Europe for childhood cancers. A questionnaire on essential medicines was sent to national representatives of paediatric oncologists, oncology pharmacists, and patients, in up to 37 European countries. Another work stream and dedicated working group focused on radiotherapy resources. Data cleaning and analysis began in view of producing the recommendations based on the collected evidence.
• Access to innovative therapies for childhood cancers through referrals to clinical trials across Europe. The strategic partner of this task was Innovative Therapies or Children with Cancer (ITCC). A first set of recommendations to increase and facilitate children’s access to innovation through clinical trials was agreed during a face-to-face meeting including major stakeholders with focus on ITCC network countries.
• Optimal care and research for young people with extreme

The main output achieved so far and their potential impact and use by target group (including benefits)

1. List of rare cancers reviewed and discussed during the consensus conference for the benefit of clarifying which cancers are rare and which are the most relevant, from an organisational point of view, families of rare cancers.

2. Recommendations for the standardized estimation of rare cancers indicators at the European and country level available supporting the standardisation of the epidemiological analyses and the data comparison in Europe.

3. Survey on availability of clinical practice guidelines for all rare cancer families finalised together with the assessment of the quality of existing clinical practice guidelines (for each family of rare cancers). This will be of great benefit for ERN experts and for clinicians in general.

4. Proposals to improve collaborative international clinical trials in the EU,
particularly inter-group clinical trials finalised for the benefit of all researchers involved in such challenging studies.

5. Map of available continuous medical education resources (for professionals and patients) on the 12 families of rare cancers available for the benefit of the ERNs members.


7. Orientations on policy measures on rare cancers for national plans and strategies on cancers and rare diseases finalised

The last two achievements will contribute to start discussion about the integration of the ERN at national level.

Achieved outcomes compared to the expected outcomes

The JARC is in line with the planned activites. The outcomes envisioned for the second reporting period have been achieved and are listed above.

Dissemination and evaluation activities carried out so far and their major results

The website focused on the dissemination of the goals, results, papers, interviews and news arising from the project to make them available to JARC partners, general public, stakeholders, researchers and patients, scientific and professional societies, Member States, EU Experts on rare cancers.

JARC activities and outcomes are annually evaluated by an external advisory board.
Work Package 1: Coordination
Start month: 1
End month: 36
Work Package Leader: INT

This WP will ensure coordination among JARC partners and coordination of JARC with the current CanCon Joint Action, the Joint Action on rare diseases and other ongoing initiatives and projects devoted to rare cancers, rare diseases and childhood cancers in Europe, and will oversee the overall technical and budgetary management of the project.

Fondazione IRCCS Istituto Nazionale dei Tumori (INT) will lead the WP. The Coordinator will be supported by: the project management team (PMT) to fulfil administrative tasks, the Steering Committee (SC) to make strategic decisions and by an advisory board involving patients associations (European Cancer Patients Coalition (ECPC), EURORDIS, Childhood Cancer International (CCI-Europe)) to ensure patients perspectives since the beginning of the project and along the different activities of each Work Package (WP).

The PMT will be established at the INT and will include the coordinator, a project manager and a financial officer. The PMT will take in charge the day-to-day operational management. The PMT supports the coordinator, the SC, the WP leaders and all partners. The work of the PMT will include the following tasks:

- Development of instruments for the project management (Document Management System, Project Management Tool).
- Preparation of the SC meetings in close collaboration with the hosting organization and writing of the minutes of the meetings.
- Provision of editorial, economic and administrative support to the WP Leaders and associated partners.
- Financial and administrative management of the project, including transaction of funds to the partners, collection of the cost statements, monitoring of the correctness and accuracy of financial reports developed by partners, submission of financial reports to the CHAFEA.
- Preparation of financial and technical reporting template, 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.
- Preparation and management of the risk plan.

The SC will consist of PMT and WP leaders and will be the decision-making body of the project. The first SC meeting will be chaired by the Co-ordinator and decision
for the designation of the chairing of other SC meetings will be taken at the first meeting. The SC will be the decision making body. All WP leaders will have equal voting rights. If possible, decisions will be reached on a consensus basis. In case of conflicts, the Co-ordinator will analyse the reasons for the conflict and seek a consensus after hearing the conflicting parties. Only if no consensus is reached, the simple majority principle shall apply. 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 agree on agendas and programmes for workshops and conferences and decide on other future actions which will be taken cooperatively. The PMT will report to the SC that oversees the work done there. The SC will meet every 9 months. During the first meeting, at the beginning of the project, activities, responsibilities and management of the project will be discussed. The other 3 meetings (every 9 months) will be used to monitoring the work and exchange information.

A General Assembly including all Associated and Collaborating Partners will be annually convened, back to back the SC meetings. The first General Assembly meeting (kick-off meeting) will aim at discussing JARC proposal and partner’s roles and collaborations. It will be organised back to back the first SC meeting.

Work Package 2: Dissemination

Start month: 1
End month: 36
Work Package Leader: UoA

Information on JARC and JARC-related deliverables and outputs will be disseminated through: development of the JARC WEB site; diffusion by e-mail of relevant documents to all key stakeholders; diffusion through relevant newsletters (Orphanet, EURORDIS, ECPC, CanCon, OECI); presentation of the project activities at major EU, national and international conferences; publication of major results in scientific/public health journals and magazines; development and diffusion of Policy briefs; meetings with Members of the European Parliament (MEP) Against Cancer, and ESO educational and communication tools (websites, CancerWorld Magazine, Media office). The diffusion of “recommendations” developed by JARC will be ensured by engaging all major stakeholders during all steps of their development, among others by meetings with stakeholders and project participants to share experiences, identify best practices, elaborate and review recommendations in a participatory way. This constant involvement of stakeholders will facilitate processes of understanding of rare cancers and their challenges and will make them part of the decision-making process with regard to best practices, creating a community “owning” the final recommendations developed within JARC. The key message of the recommendations (WP10) in English and in all the languages of the associated partners will be published in the JARC website. Copies of the key messages and recommendations will be published on CD-rom and distributed to the Commission bodies, Ministries of Health and co-ordinators of national cancer programs in the EU MSs. The recommendations will be presented at the Expert
Group on Cancer.

The dissemination activities will include the following tasks:

Task 2.1 Prepare the JARC leaflet and information material about its outputs. Development of communications and news for articles, journal and media release to inform stakeholders on JARC activities and main results. Development of policy briefs, presentations at relevant congresses. Lead partner: UoA + European cancer Patients Coalition (ECPC), OECI, European School of Oncology (ESO), UP, INT, Rare Cancer Europe (RCE)

Task 2.2 Plan, build and maintain the JARC website Lead partner UoA + all WP2 partners, ECPC, ESO

Task 2.3 Organize the final JARC meeting. The meeting will include Commission bodies, Ministries of Health, co-ordinators of national cancer programs in the EU MSs, patients representatives, and ERNs representatives and all partners. It will aim at presenting the JARC recommendations to all interested stakeholders. Lead partner UoA , INT + JARC SC.

The internal communication will be ensured, in collaboration with the JARC PMT (WP1), by establishing a mailing list including all partners (associated and collaborating), which will be continuously updated and used to share communications relevant to all partners. A restricted section of the web-site will be developed to allow on-line interactions with partners.

The detailed dissemination plan is reported in the annexed Table.

Work Package 3: Evaluation
Start month: 1
End month: 36
Work Package Leader: CSF

The evaluation of the JARC will focus on: 1) project implementation; 2) quality of project deliverables.

The following audience will be considered:
- all stakeholders that will be in touch with JARC through workshops, data collection, project WEB site surfing;
- a panel of 3 external experts to set up a project advisory committee that will be consulted once per year (3 meetings of the advisory committee envisioned at month 12; 24; 36). An overall evaluation strategy will be developed at the beginning of the JARC in collaboration with WP1. It will be based on process, output and outcome indicators for each objective (a tentative list of indicators is enclosed and will be discussed with WP3 advisory committee).
The following means will be used:
- satisfaction questionnaire to be delivered and compiled during all the meetings and workshops;
- a specific area of the public section website dedicated to collect on line users opinions and comments on the project web-site;
- final survey.

The process and outcome indicators will affect:
Level of satisfaction of the project activities
Each time a workshop with external stakeholders and/or experts will be organised their feedback on the workshop content, organisation, quality and relevance will be collected. In addition a dedicated area will be available on the public section of the website to collect users feedback on the quality of the project website in terms of relevance, clarity and completeness.

Quality of the project reports
The deliverables of the projects will be peer-reviewed by the Steering Committee of the JARC (see WP1). In addition, all deliverables will be sent to the advisory committee asking for a feedback on content clarity, relevance to RD policies, and usefulness.

The national meetings will offer information on the relevance of the recommendations in the local setting.

Interest on the project activities and report
Statistics on number and typology of the website users and workshop participants and number of download will be used to evaluate the interest on the project.

Awareness and impact of the proposed recommendations on the planning activities of the partners countries.
A survey directed to all those attending the final JARC meeting and those who received the CD-Rom of the recommendations including Commission bodies, Ministry of Health and co-ordinators of RD national programme in EU MS.

Work Package 4: Epidemiology
Start month: 1
End month: 36
Work Package Leader: INT

Task 4.1. Definition and list of rare cancers. Starting from the proposal of the RARECARE and RARECAREnet projects, an operational definition of rare cancers will be agreed, one that can be used for public health issues, for the development of ERNs, for the orphan drug designation process, for improving rare cancer classification (including that of childhood and adolescent and young adults) and surveillance. European Medicine Agency (EMA), DG SANTE Unit on pharmaceuticals, European Cancer Patients Coalition (ECPC), scientific societies, European Network
of Cancer Registry (ENCR), epidemiologists and Orphanet will be involved (via
surveys and meeting). INT (Lead Partner-LP), SIOPE, INCa, UoA, Suomen
Syopayhdistys Ry (Finish Cancer Registry-FCR), ENCR, INSERM, FISABIO, VULSK,
USZ, University College of London-Institute of Child Health (UCL-ICH).

Task 4.2. Cancer registration. This task will provide recommendations to improve
the quality of registration of rare cancers and to strengthen their epidemiological
surveillance. Starting points will be the reports on data quality provided by the
RARECARE project [www.rarecare.eu] and on the recent workshop hold at the JRC
on harmonisation of data collection between ENCR, various European projects
(EUROCARE, RARECAREnet, HAEMACARE, etc.) and national cancer networks. The
data necessary to monitor rare cancers and explain differences across MS, mainly
in term of incidence and survival, are the quality of morphological details, stage,
treatment and place of treatment. Some CRs routinely collect these data. Thus their
quality and comparability will be assessed from available datasets (EUROCARE/JRC
database) by comparing the distribution of the identified variables across countries
and discussing the results with expert registrars, clinicians and pathologists.
Possible actions to make these variables regularly available to all CRs, will be
discussed. Similarities and differences between registration procedures for rare
diseases and rare cancers will be outlined and discussed. The experience gained
during the long history of cancer registration will be shared with the group of rare
disease registration. The work ongoing in the rare diseases field on the
interoperability between registries, databases, and biobanks, including the ORPHA
codification, will benefit rare cancers. FFIS (LP), INT, EASP, NCRB, IPH (Belgian
Cancer Registry- BCR), Suomen Syopayhdistys Ry (FCR), SIOPE, UoA, INSERM,
Joint Research Centre (JRC), ENCR, FISABIO, VULSK, CNIPH, University College of
London-Institute of Child Health (UCL-ICH).

Task 4.3. Methods to provide epidemiological descriptive and outcome indicators on
rare cancers. Estimating epidemiological indicators of incidence, survival and
prevalence for rare cancers may be challenging, particularly for exceptionally rare
entities (i.e. incidence
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Country: France
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<td>EURORDIS - EUROPEAN ORGANISATION FOR RARE DISEASES</td>
<td>Street: 96 rue Didot City: 75014 Paris</td>
<td>France</td>
<td><a href="http://www.istitutotumori.mi.it">http://www.istitutotumori.mi.it</a></td>
</tr>
<tr>
<td>FUNDACION PARA LA FORMACION E INVESTIGACION SANITARIAS DE LA REGION DE MURCIA</td>
<td>Street: CALLE LUIS FONTES PAGAN City: 30003 MURCIA 6097</td>
<td>Spain</td>
<td><a href="http://www.istitutotumori.mi.it">http://www.istitutotumori.mi.it</a></td>
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Street: CALLE LUIS FONTES PAGAN
City: 30003 MURCIA
6097
Country: Spain
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INSTITUT NATIONAL DU CANCER GIP
Street: 52, avenue André Morizet
City: 92513 Boulogne-Billancourt
Country: France
Website: http://www.istitutotumori.mi.it
Website:  http://www.istitutotumori.mi.it

INSTITUT NATIONAL DU CANCER GIP
Street: 52, avenue André Morizet
City: 92513 Boulogne-Billancourt

Country: France
Website:  http://www.istitutotumori.mi.it

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Street: 52, avenue André Morizet
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Country: France
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ARISTOTELIO PANEPISTIMIO THESSALONIKIS
Street: Aristotle University Campus, Tritis Septemvriou, KEDEA Building
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Country: Greece
Website: http://www.istitutotumori.mi.it
Country: Greece
Website: http://www.istitutotumori.mi.it

FUNDACION PARA EL FOMENTO DE LA INVESTIGACION SANITARIA Y BIOMEDICA DELA COMUNITAT VALENCIANA
Street: Micer Mascó 31
City: 46010 Valencia

Country: Spain
Website: http://www.istitutotumori.mi.it
Country: Spain
Website: http://www.istitutotumori.mi.it

FUNDACION PARA EL FOMENTO DE LA INVESTIGACION SANITARIA Y BIOMEDICA DELA COMUNITAT VALENCIANA
Street: Micer Mascó 31
City: 46010 Valencia
Country: Spain
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City: 10115 Berlin
Country: Germany
Website: http://www.istitutotumori.mi.it
UNIVERSITATEA BABES BOLYAI  
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City: 400084 CLUJ-NAPOCA  
Country: Romania  
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Ministry of Health of the Republic of Cyprus  
Street: 1 Prodromou Street & 17 Chilonos Street 1 & 17  
City: 1448 Nicosia  
Country: Cyprus  
Website: http://www.istitutotumori.mi.it

Ministry of Health of the Republic of Cyprus  
Street: 1 Prodromou Street & 17 Chilonos Street 1 & 17  
City: 1448 Nicosia  
Country: Cyprus  
Website: http://www.istitutotumori.mi.it

HEALTH SERVICE EXECUTIVE HSE  
Street: Dr Steevens' Hospital  
City: DUBLIN 8  
Country: Ireland  
Website: http://www.istitutotumori.mi.it

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Street: Dr Steevens' Hospital  
City: DUBLIN 8  
Country: Ireland  
Website: http://www.istitutotumori.mi.it
PANCARE
Street: Jacobus Bellamylaan 16
City: 1401 AZ Bussum
Country: Netherlands
Website: http://www.istitutotumori.mi.it

Ministry for Health - Government of Malta
Street: Palazzo Castellania, 15 Merchants Street
City: VLT 1171 Valletta
Country: Malta
Website: http://www.istitutotumori.mi.it
<table>
<thead>
<tr>
<th>Organization</th>
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<tr>
<td>DEUTSCHE KREBSGESELLSCHAFT EV</td>
<td>Kuno-Fischer-Str. 8</td>
<td>14057 Berlin</td>
<td>Germany</td>
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<td>0424 OSLO</td>
<td>Norway</td>
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</table>
Report on consensus/recommendations on the key criteria used for the organisation, governance and harmonization of rare cancer care policies at national and the EU level
ICO
Joint Action on Rare Cancers (JARC)
Published on: 21/01/2020
This report will foresee policy recommendations from WP10 and from other WPs in order to coordinate health policies on rare cancers in the EU

JARC evaluation report
CSF
Joint Action on Rare Cancers (JARC)
Published on: 21/01/2020
This report will report on whether the project has reached the objectives

Lay version of the final report
INT
Joint Action on Rare Cancers (JARC)
Published on: 10/10/2019
This will be a short version of the final report, targeted to the interested lay public

Report of the Final JARC conference
UoA
Joint Action on Rare Cancers (JARC)
Published on: 10/10/2019
This report will deal with the final conference on rare cancers at the end of JARC

Recommendations on how to exploit CRs data for research and for the development and
assessment of future ERNs
INT
Joint Action on Rare Cancers (JARC)
Published on: 10/10/2019
This report will describe how to ensure high quality of rare-cancer registration by CR, how to estimate indicators and how to perform ad-hoc studies on rare cancer using population based CR data

Report summarising the results of the survey on accessibility of standard treatment and recommendations to Member States and Europe to overcome bottlenecks
SIOPE
Joint Action on Rare Cancers (JARC)
Published on: 10/10/2019
This report will include the results of the survey on bottlenecks faced by children with cancer and families in getting standard treatment and solutions

Report summarizing recommendations to facilitate referral of children to trial centers offering innovative medicines
SIOPE
Joint Action on Rare Cancers (JARC)
Published on: 10/10/2019
This report will include recommendations to improve access of children with cancer to innovative medicines

Report summarising proposals to address extremely rare cancers in young patients
SIOPE
Joint Action on Rare Cancers (JARC)
Published on: 10/10/2019
This report will provide recommendations to deliver optimal care and research for young people with extremely
Guidelines and recommendations on models of healthcare to assure adequate follow-up of children surviving cancer, transition to adult medicine, and the use of a Survivorship Passport

SIOPE
Joint Action on Rare Cancers (JARC)
Published on: 10/10/2019
These will be recommendations on models of healthcare for survivors of childhood cancers

Report on policy and organisational issues affecting the development of ERNs

ICO
Joint Action on Rare Cancers (JARC)
Published on: 17/04/2019
This report will include the results of the case-studies and propose models for harmonization, governance and coordination of ERNs

Report on orphan drug designation and marketing authorization process for medicinal products for rare cancers

ICO
Joint Action on Rare Cancers (JARC)
Published on: 17/04/2019
This report will provide an update of the process of orphan drug designation in the EU as well as of discrepancies in marketing.

Definition of a model for linking clinical and population based CR data

UVEG
Joint Action on Rare Cancers (JARC)
Published on: 17/04/2019
This report will address the technical feasibility of the linkage, its completeness and its overall quality including issues related to possible problems of data sharing and the essential information that a clinical database has to include to
ensure possible linkages and/or comparisons with population-based CRs

A framework of systems-based quality standards applicable to all networks and centres for rare cancers adding to ERN requirements
OECI
Joint Action on Rare Cancers (JARC)
Published on: 17/04/2019
This report will describe standards on accuracy of diagnosis, continuity of care, holistic and psycho-social support specific for the 12 families of rare cancers (including childhood cancers)

Recommendations on optimal implementation of clinical practice guidelines on rare cancers
DKG
Joint Action on Rare Cancers (JARC)
Published on: 17/04/2019
This report will provide solutions addressing the issues about implementation of clinical practice guidelines at the local level

Report summarizing the status of the development of UEMS-EU harmonized educational principles and recommended training materials for rare cancers
UP
Joint Action on Rare Cancers (JARC)
Published on: 17/04/2019
This report will include the UEMS-EU recommendations for training materials for rare cancers

Recommendations to improve the quality of rare-cancer registration in population based CRs
<table>
<thead>
<tr>
<th>Joint Action on Rare Cancers (JARC)</th>
<th>Published on: 17/04/2019</th>
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<tr>
<td><strong>This report will include recommendations for population based CRs to increase the quality and completeness of rare cancers registration</strong></td>
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<td><strong>A proposal for quality assurance processes specific to rare cancers and consistent with ERN requirements focusing on improving quality of care, based on peer review and patient involvement</strong></td>
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<td><strong>This report will provide recommendations on how to integrate big data from pathology files, tumour registries, electronic patient records and administrative health data bases</strong></td>
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</table>
Roadmap on precision medicine in rare cancer care within ERNs
WIV-ISP (IPH)
Joint Action on Rare Cancers (JARC)
Published on: 17/04/2019
This report will provide recommendations on how to integrate translational research innovations on rare cancers

Report on development of educational tools and learning programmes for the rare-cancer patient communities
UP
Joint Action on Rare Cancers (JARC)
Published on: 17/04/2019
This report will include criteria for educational tools and learning programmes for patient advocates and patient communities

Recommendations for the standardized estimation of rare cancers indicators at the European and country level
INT
Joint Action on Rare Cancers (JARC)
Published on: 13/12/2018
This report will provide guidelines to estimate incidence, prevalence, survival for rare cancers with different approaches. It will include recommendations also on the use of high resolution studies

Map/Database of expert centres and networks on rare cancers in Europe
OECI
Joint Action on Rare Cancers (JARC)
Published on: 13/12/2018
This will be a list of centres and networks of treatment centres involved in the clinical management of the 11 families of solid rare cancers in different EU MS
Report on the assessment of the quality of existing clinical practice guidelines (for each family of rare cancers)
DKG
Joint Action on Rare Cancers (JARC)
Published on: 13/12/2018
This report will include possible solutions to open issues about the implementation of clinical practice guidelines at the local level

Report on QA/QC guidance for collection of biological samples and data on rare cancers in the EU
WIV-ISP (IPH)
Joint Action on Rare Cancers (JARC)
Published on: 13/12/2018
Report on standardization of clinical data and patient-centered clinical outcomes for big data optimal exploitation and connection to virtual biobanks and quality assurance / quality control (QA/QC) in regard to biological samples, data collection and molecular screening (with special reference to SPECTARare)

Map of available continuous medical education resources on the 12 families of rare cancers and recommendations on their integration within ERNs
UP
Joint Action on Rare Cancers (JARC)
Published on: 13/12/2018
This report will include a list of medical educations tools available per each of the 12 families of rare cancers, with possible solutions to help integrate them within the ERN

List of existing preclinical paediatric cancer models and skilled research teams involved in
preclinical research
SIOPE
Joint Action on Rare Cancers (JARC)
Published on: 13/12/2018
This list will cover preclinical paediatric cancer models and skilled research teams performing preclinical research

JARC second evaluation report
CSF
Joint Action on Rare Cancers (JARC)
Published on: 13/12/2018
This report will report on how the project is performing against the indicators set

Recommendations on policy measures on rare cancers for national plans and strategies on cancer and rare diseases
ICO
Joint Action on Rare Cancers (JARC)
Published on: 27/07/2018
This report will propose a core set of strategies for rare cancers to accommodate within the national cancer plans and rare disease plans across the EU Member States

List of rare cancers (based on the consensus operational definition of rare cancers)
INT
Joint Action on Rare Cancers (JARC)
Published on: 10/04/2018
This report will describe the operational definition of rare cancers agreed upon on a consensus basis and will include a list of rare cancers

List of differences and commonalities between rare cancers registration and rare diseases registration
INT
This report will describe rare cancers and rare diseases registration similarities and differences.

Report and survey on availability of clinical practice guidelines for all rare cancer families
DKG

This report will include a list of clinical practice guidelines available for RCs along with scores reflecting their quality.

Proposals to improve collaborative international clinical trials in the EU, particularly inter-group clinical trials
WIV-ISP (IPH)

This report will provide solutions to regulatory constraints for inter-group clinical trials in the EU.

JARC first evaluation report
CSF

This report will report on how the project is performing against the indicators set.

Project website
UoA

The web-site will provide information on JARC.
Dissemination plan of the JARC
UoA
Joint Action on Rare Cancers (JARC)
Published on: 14/03/2017
This report will describe the dissemination plan and the stakeholder analyses

Leaflet of JARC available
UoA
Joint Action on Rare Cancers (JARC)
Published on: 11/01/2017
The leaflet will describe JARC objectives, main activities and partners