



JARC
JOINT ACTION ON RARE CANCERS



FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI

FUNDING UNDER THE 3RD HEALTH PROGRAMME 2014-2020



*Actions co-financed with
Member State authorities
(Joint Actions)*

The Health Programme is about fostering health in Europe by encouraging cooperation between Member States to improve the health policies that benefit their citizens. The programme aims to support and complement Member States health initiatives.

The Programme is translated into annual work programmes defining actions in priority areas set in the Programme Regulation (EU) No282/2014. On this basis the Consumer, Health and Food Executive Agency organises every year calls for proposals.

Joint Actions are one funding instrument under the third EU Health Programme 2014-2020.

WHAT IS A JOINT ACTION?

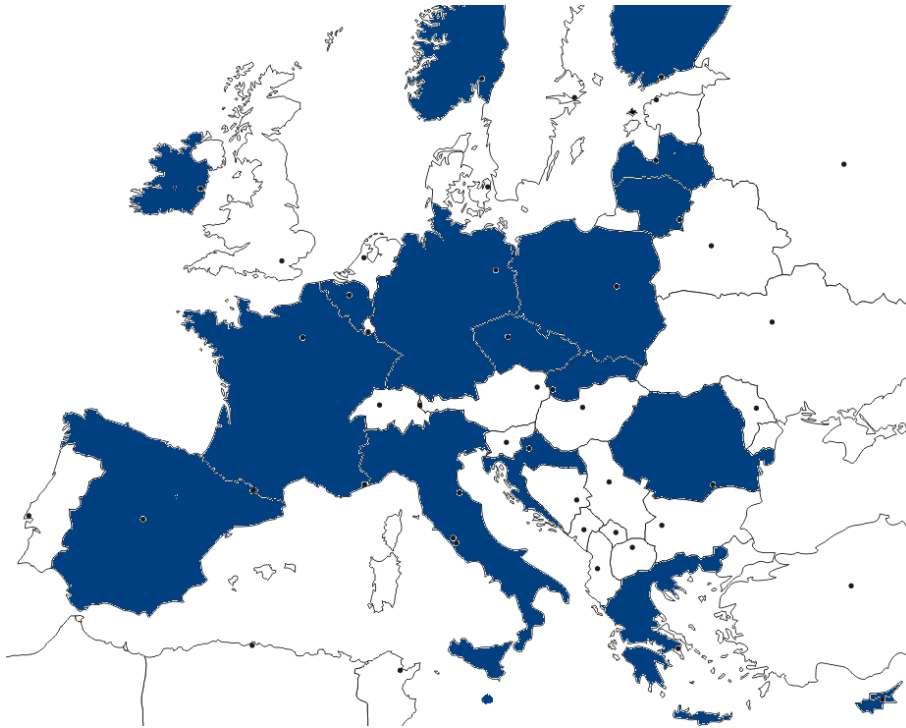
Joint Actions have a clear EU added value and are co-financed either by competent authorities that are responsible for health in the Member States or in the third countries participating in the Programme, or by public sector bodies and non-governmental bodies mandated by those competent authorities.

Joint Actions' proposals should provide a genuine **European dimension** in order to make sense both technically and in terms of policy. Depending on the scope of the action previous Joint Actions involved on average 25 partners.

HOW TO PARTICIPATE?

The Commission sends invitation letters to all EU Member States and other countries participating in the 3rd Health Programme, asking them to nominate the participants in the Joint Actions listed in the annual work programme.

Partnerships



- **18 MSs**
- **34 ass. partners**
- **24 coll. partners**

LIST OF BENEFICIARIES

Number	Short Name	Legal Name	Country
1	INT	FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI	IT
2	UoA	ETHNIKO KAI KAPODISTRIAKO PANEPISTIMIO ATHINON	EL
3	OECI	GROUPEMENT EUROPEEN D INTERET ECONOMIQUE ORGANISATION OF EUROPEAN CANCER INSTITUTES	BE
4	WIV-ISP (IPH)	INSTITUT SCIENTIFIQUE DE SANTE PUBLIQUE	BE
5	UP	PECSI TUDOMANYEGYETEM - UNIVERSITY OF PECS	HU
6	SIOPE	SIOP Europe	BE
7	ICO	INSTITUT CATALA D'ONCOLOGIA	ES
8	CSF	SUOMEN SYOPAYHDISTYS RY	FI
9	CNIPH	HRVATSKI ZAVOD ZA JAVNO ZDRAVSTVO	HR
10	EASP	ESCUELA ANDALUZA DE SALUD PUBLICA SA	ES
11	EURORDIS	EURORDIS - EUROPEAN ORGANISATION FOR RARE DISEASES ASSOCIATION	FR
12	FFIS - CARM	FUNDACION PARA LA FORMACION E INVESTIGACION SANITARIAS DE LA REGION DE MURCIA	ES
13	INCa	INSTITUT NATIONAL DU CANCER	FR
14	INSERM	INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE	FR
15	NCRB	NATIONAL CANCER REGISTRY BOARD	IE
16	USZ	SZEGEDI TUDOMANYEGYETEM	HU
17	OOI	ORSZAGOS ONKOLOGIAI INTEZET	HU
18	UVEG	UNIVERSITAT DE VALENCIA	ES
19	VULSK	VIESOJI ISTAIGA VILNIUS UNIVERSITETO LIGONINES SANTARISKIU KLINIKOS	LT
20	VHIR	FUNDACIO HOSPITAL UNIVERSITARI VALL D'HEBRON - INSTITUT DE RECERCA	ES
21	MZCR	MINISTRY OF HEALTH OF THE CZECH REPUBLIC	CZ
22	AUTH	ARISTOTELIO PANEPISTIMIO THESSALONIKIS	EL
23	FISABIO	FUNDACION PARA EL FOMENTO DE LA INVESTIGACION SANITARIA Y BIOMEDICA DELA COMUNITAT VALENCIANA	ES
24	GPOH	GERMAN SOCIETY OF PEDIATRIC ONCOLOGY HEMATOLOGY	DE
25	MIN SALUTE	MINISTERO DELLA SALUTE	IT
26	UBB	UNIVERSITATEA BABES BOLYAI	RO
27	MoH Cyprus	MINISTRY OF HEALTH OF THE REPUBLIC OF CYPRUS	CY
28	HSE	HEALTH SERVICE EXECUTIVE HSE	IE
29	LSMU	LIETUVOS SVEIKATOS MOKSLU UNIVERSITETO LIGONINE KAUNO KLINIKOS	LT
30	MZ	THE MINISTRY OF HEALTH OF THE REPUBLIC OF POLAND	PL
31	PanCare	PANCARE	NL
32	MFH	MINISTRY FOR HEALTH - GOVERNMENT OF MALTA	MT
33	DKG	DEUTSCHE KREBSGESELLSCHAFT E.V.	DE
34	OUS	OSLO UNIVERSITETSSYKEHUS HF	NO

Incidence (number of new cases/year < 6/100,000)

EUROPEAN JOURNAL OF CANCER 47 (2011) 2493–2511



ELSEVIER

Available at www.sciencedirect.com

SciVerse ScienceDirect

journal homepage: www.ejconline.com



Rare cancers are not so rare: The rare cancer burden in Europe

Gemma Gatta ^{a*}, Jan Maarten van der Zwan ^b, Paolo G. Casali ^c, Sabine Siesling ^b,
Angelo Paolo Dei Tos ^d, Ian Kunkler ^e, Renée Otter ^b, Lisa Licitra ^f, Sandra Mallone ^g,
Andrea Tavilla ^g, Annalisa Trama ^a, Riccardo Capocaccia ^g, The RARECARE working group

Fonte: Gatta et al. rare cancers are not so rare: The rare cancer burden in Europe. EJC 2011;47: 2493-2511 www.rarecarenet.eu

Number of expected cases in 2013 for different incidence rates

	incidence rate		
	0.1/100.000 Bone sarcomas	0.45/100,000 Nasal cavity tumors	3.5/100,000 Acute myeloid leukaemia
European Union (28)	558	2,282	17,801
Belgium	12	50	392
Spain	51	210	1,640
France	72	295	2,302
Italy	66	269	2,095
Portugal	12	47	368
Romania	22	90	703

JARC Rationale

- Rare Cancers are many (24% of all new cancer diagnoses)
- Low survival rate for most Rare Cancers
- The rarity of the disease induces late and/or wrong diagnosis which has a dramatic impact on the life of the patients
- Great inequalities in provision of healthcare
- Wide consensus that expertise needs to be mapped out for effectively treating rare cancers
- Need for fostering research through large international collaborations
- ERNs represent a great opportunity for improving healthcare, fostering research and ultimately reducing healthcare inequalities



European
Reference
Networks

*“will provide
highly specialised healthcare
for rare or low prevalence
complex diseases or conditions”*

JARC
JOINT ACTION ON RARE CANCERS



Objectives

- to prioritise rare cancers in the agenda of the EU and Member States;
- to develop innovative and shared solutions, mainly to be implemented through the future ERNs on rare cancers

We aim to develop solutions to improve:

- Epidemiological surveillance
- Quality of care through ERNs
- Clinical practice guidelines
- Innovation
- Medical and Patient education
- Health policy measures
- Patient empowerment

Rare cancers: 12 families

1. Pediatric cancers
2. Haematologic rare neoplasms
3. Sarcomas
4. Rare thoracic cancers
5. Neuroendocrine tumours
6. Head & neck cancers
7. Central nervous system tumours
8. Rare female genital cancers
9. Rare urological and male genital tumours
10. Endocrine gland tumours
11. Digestive rare cancers
12. Rare skin cancers & non-cutaneous melanoma

Rare solid cancers
75% of all rare cancers

Work packages

Coordination

INT, IT

Dissemination

NKUA, GR

Evaluation

CSE, IT

Epidemiology

Assuring Quality of Care

Patient empowerment *ECPC, EURORDIS*

Common Cancers

DKFZ, DE

Rare Cancer Policy

WIV-ISP, BE

SZTE, HU

SIOPE

ICO, ES

Work package 4 Epidemiology

- to agree on an operational definition of rare cancers,
- to develop recommendations to improve the quality of rare-cancer registration in population based cancer registries (CRs),
- to propose a model to evaluate the impact of ERNs by linkage of CRs with clinical data.

- To map the existing networks of care for all 12 families of rare cancers
- To design Quality Assurance systems or processes specific to rare cancers
 - The aim would be to promote and assure the standards will be maintained, a system of continuous quality improvement be established, best practice shared, and equality of care met for rare cancers across Europe
- Establish PAGs for rare cancers

- to map and provide a quality evaluation of existing clinical practice guidelines for rare cancer subtypes;
- to identify open issues about implementation of clinical practice guidelines at the local level;
- to work out solutions on how to incorporate clinical practice guidelines within ERNs.

- to stimulate translational research on rare cancers by exploiting networking, namely through the new ERNs
- to explore the possibility to set up a clinical epidemiology framework program for outcome research in rare cancers integrating big data;
- to make proposals on how to exploit available regulations across the EU, and/or how to improve them, on collaborative prospective interventional clinical research.

Work package 8 Medical education

- to promote the improvement of European medical expert training,
- to provide recommendations on education of non-medical experts,
- identify the needs for educational tools and learning programme of the rare cancer patient communities

Work package 9 Childhood cancers

- To define collaborative measures for ensuring access of **standard** treatments (essential medicines and radiotherapy) and accelerating access to **innovative** therapies;
- To recommend solutions for delivering optimal care and research for **young people with extremely rare cancers** (<2/1,000,000)
- To consolidate guidelines and recommendations on models of healthcare for **survivors of childhood cancers**, including long-term follow-up, transition to adult medicine, and the use of a Survivorship Passport

Work package 10 Rare cancer policy

- to propose a core set of strategies and measures to accommodate rare cancers-specific needs in the national cancer plans and rare disease plans across the EU Member States;
- to analyze current problems in the designation of orphan drug medical products and in marketing of medicinal products for rare cancers to identify possible ways to address the major issues;

Deliverables...



2016

JANUARY							FEBRUARY							MARCH							APRIL													
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							30	31																										

Kick-off meeting

8.30 **Welcome from the Commission and the Coordinator**

9.00 **Work package presentations and discussion**

WP1 – Coordination of the JARC and partners involvement

WP4 – Epidemiology

WP5 – Assuring Quality of Care

WP6 – Clinical practice guidelines

WP7 – Innovation and access to innovation

10.30 *Coffee break*

WP8 – Medical education

WP9 – Childhood Cancers

WP10 – Rare Cancer Policy

WP2 – Dissemination

WP3 – Evaluation

12.00 **Administrative and financial issues**

12.30 *Lunch and transfer of participants to the venue of the official launch of JARC*

Launch event

7th November, 2016
Luxembourg
Neumunster Abbey, Hall Dune

Moderators: G. Apolone, A. Montserrat

14.00	<i>G. Apolone, A. Montserrat</i>	Welcome
14.15	<i>G. Gatta</i>	The epidemiological landscape
14.30	<i>Y. Le Cam</i>	The rare disease perspective
14.45	<i>F. De Lorenzo</i>	The cancer patient perspective
15.00	<i>L. Mutsch</i>	Welcome from the Minister of Health of Luxembourg
15.15		Videoconference with the Minister of Health of Italy, Rome
15.30	<i>V. Andriukaitis</i>	Rare cancers and the EU Directive on Cross-Border Healthcare
16.00	<i>P.G. Casali</i>	Objectives of the EU Joint Action on Rare Cancers
16.30		coffee break
		<i>Facilitator: Annie Pannelay (Economist Intelligence Unit)</i>
		<i>Rare Cancers Europe round table discussions</i>
17.00		The opportunity and the challenges of ERNs
17.45		The European rare cancer community, JARC and ERNs
18.30		<i>Discussion with the audience</i>
19.00		<i>Closure of the meeting and Rare Cancers Europe networking dinner</i>



Show your support and sign the
Call to Action Against Rare Cancers:

www.rarecancerseurope.org

Rare Cancers Europe is a joint initiative based on a partnership between the European Society for Medical Oncology (ESMO), the European Organisation for Rare Diseases (EURORDIS), the European Cancer Patient Coalition (ECPC), the European Organisation for Research and Treatment of Cancer (EORTC), Conticanet, EuroBoNeT, the World Sarcoma Network (WSN), the Association of European Cancer Leagues (ECL), the Chronic Myeloid Leukaemia Support Group, the International Brain Tumour Alliance (IBTA), Orphanet, the Chronic Myeloid Leukaemia Advocates Network, the Sarcoma Patients EuroNet Association (SPAEN), GIST Support UK & PAWS-GIST, Cancer 52, the International Kidney Cancer Coalition (IKCC), the Chordoma Foundation, the Fondazione IRCCS Istituto Nazionale dei Tumori, the European Institute of Oncology (IEO), the European Society for Paediatric Oncology (SIOP Europe), the European Society of Surgical Oncology (ESSO), the Grupo Español de Tumores Huérfanos e Infrecuentes (GETHI), the European School of Oncology (ESO), the European Oncology Nursing Society (EONS), eCancer, the European Society of Pathology (ESP), the European, Middle Eastern and African Society for Biopreservation and Biobanking (ESBB), Novartis Oncology (initiating sponsor and industry partner), Pfizer Oncology (industry partner), and Sanofi (industry partner). The campaign is moreover supported by additional corporate supporters, including Amgen (silver industry supporter) and Takeda Pharmaceuticals Europe (silver industry supporter).

RARE CANCERS

More common than you think!



PROMOTING IMPLEMENTATION OF RECOMMENDATIONS ON POLICY,
INFORMATION AND DATA FOR RARE DISEASES



**RD-ACTION works towards an integrated, European approach
to the challenges faced by the rare disease community.**

**By supporting the development of European and national policies,
RD-ACTION brings together efforts to improve knowledge on rare diseases
and orphan drugs, and support the rare disease community.**

**A 3-year
European Joint Action
(June 2015 – May 2018)**

**34 beneficiaries
30 collaborating partners
40 countries**

This leaflet is part of the project/joint action '677024 / RD-ACTION' which has received funding from the European Union's Health Programme (2014-2020). The content of presentation represents the views of the author only and is his/her sole responsibility. It can not be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

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**Co-funded by
the Health Programme
of the European Union**

WHO WE ARE

HOW WE WORK

NEWS & EVENTS

TOOLS

CONTACT INFO

EXTRANET 

IMPROVING CANCER CONTROL

THIS IS CANCON.

Cancer experts from across Europe and beyond have joined forces to advance cancer control. Cancon is the result – an initiative aimed cutting the cancer burden by raising the standards of care, treatment and quality of life of patients

Rare cancers as a recognized issue...



Available at www.sciencedirect.com

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journal homepage: www.ejconline.com



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Table 1 - Data quality indicators and other characteristics of malignant cancers diagnosed in European cancer registries 1995-2003 and included in the analysis.

Country	Registry	Number of malignant cancers	Data quality indicators					
			Death certificate only (%)	Accuracy (%)	Multinomial verification (%)	Cases 1995-1996 reassessed before 1998 (%)	Morphology code NCI ¹ (%)	Topography code ICD ² (%)
Austria	Austria	106,698	0.9	0.0	85.3	5.9	81.1	0.8
Belgium	France	146,735	0.0	0.2	89.8	0.0	7.3	0.3
	Bas-Rhin	15,113	0.0	0.0	95.8	5.3	3.9	0.2
	Wallonia	10,081	0.0	0.0	88.1	4.1	2.0	0.8
	Communauté flamande	2,811	0.0	0.0	87.0	6.4	10.5	0.3
	Centre de la Région wallonne	4,973	0.0	0.0	87.8	6.5	9.0	0.2
	Centre de la Région wallonne	1,864	0.0	0.0	100.0	7.2	0.0	0.5
	Province de Liège	1,762	0.0	0.0	95.9	0.3	2.0	0.5
	Province de Namur	3,073	0.0	0.0	90.4	3.9	1.9	0.1
	Province de Luxembourg	10,545	0.0	0.0	94.1	4.4	1.5	0.1
	Province de Flandre-Orientale	13,728	0.0	0.0	100.0	6.8	0.2	0.1
	Province de Flandre-Occidentale	1,762	0.0	0.0	100.0	6.8	0.0	0.0
	Province de Hainaut	6,817	0.0	0.0	90.5	3.7	0.4	0.0
	Province de Namur	1,081	0.0	0.0	100.0	5.8	0.0	0.0
	Province de Luxembourg	1,081	0.0	0.0	94.2	6.0	1.5	0.8
Province de Namur	4,973	0.0	0.0	91.8	2.0	1.9	1.9	
Denmark	Denmark	74,102	5.9	0.0	91.8	5.9	6.0	0.5
Ireland	Ireland	884	0.1	1.4	96.6	0.0	3.5	0.0
Italy	Italy	136,336	2.0	0.3	86.7	0.0	11.0	0.7
Italy	Abruzzo	18,491	0.7	0.6	88.5	0.0	3.9	0.5
	Basilicata	11,791	1.1	0.4	87.0	0.0	2.0	0.3
	Calabria	13,761	1.1	0.6	86.1	0.4	3.7	0.6
	Emilia-Romagna	46,947	0.9	0.1	89.8	0.4	3.7	0.8
	Liguria	78,862	0.6	1.9	91.0	0.0	3.8	2.3
	Lombardia	44,267	1.4	0.0	87.4	0.0	10.0	3.9
	Marche	10,369	1.1	0.0	87.4	0.0	11.3	0.6
	Molise	14,247	0.5	0.0	88.6	0.4	2.8	0.2
	Puglia	2,487	3.9	0.0	73.0	1.9	17.0	1.4
	Regioni del Sud	100	0.0	0.0	88.0	0.0	7.0	0.0
	Regioni del Nord	13,896	1.0	0.0	88.0	0.1	10.1	0.7
	Regioni del Centro	10,647	1.9	0.0	89.0	0.1	8.6	0.4
	Regioni del Nord-Est	23,111	0.2	0.0	88.1	0.0	10.8	0.5
	Regioni del Sud-Est	40,447	1.4	0.0	87.9	0.1	10.1	0.5
Sardegna	26,817	2.5	0.0	77.5	4.0	20.7	1.1	
Sicilia	18,884	2.9	0.2	88.4	0.0	10.4	0.7	
Trentino-Alto Adige	17,788	2.0	0.0	85.0	0.1	17.8	3.8	
Toscana	41,111	0.7	0.0	89.0	0.1	10.4	0.8	
Umbria	14,716	1.1	0.0	88.0	1.3	10.8	0.4	
Valle d'Aosta	6,336	1.5	0.2	87.5	0.6	10.7	1.7	

Eur J Cancer 2011;47:2493



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