



The «Call to Action»: *Rare cancers in all policies*



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a “Call to Action”...



RARE CANCERS IN ALL POLICIES



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

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Eur J Cancer 2011;47:2493

Table 3 - Data quality indicators and other characteristics of malignant cancer diagnosed in European cancer registries 1997-2002 and included in the analysis.

Country	Region	Number of malignant cancers	Data quality indicators					
			Death certificate only (%)	Autopsy (%)	Microscopic verification (%)	Cases since 1997 (%)	Morphology code ICD-O (%)	Topography code ICD-O (%)
Austria	Austria	304,638	4.9	0.0	65.7	5.9	93.1	0.6
Belgium	Flanders	140,735	0.0	0.2	89.8	0.0	7.1	0.0
France	Alsace	13,133	0.0	0.0	95.8	3.3	3.9	0.2
	Alsace-Moselle	10,005	0.0	0.0	96.1	4.3	2.0	0.0
	Alsace-Moselle	2,881	0.0	0.0	87.0	4.4	0.5	0.3
	Alsace-Moselle	4,921	0.0	0.0	82.8	0.5	0.5	0.2
	Alsace-Moselle	1,884	0.0	0.0	100.0	7.7	0.0	0.5
	Alsace-Moselle	1,702	0.0	0.0	95.8	7.1	3.2	0.0
	Alsace-Moselle	973	0.0	0.0	96.4	5.8	2.8	0.1
	Alsace-Moselle	15,525	0.0	0.0	20.0	6.4	1.2	0.1
	Alsace-Moselle	13,526	0.0	0.0	94.1	4.4	4.1	0.1
	Alsace-Moselle	2,999	0.0	0.0	100.0	6.8	0.0	0.0
Germany	Baden-Württemberg	6,987	0.0	0.0	96.1	3.7	3.6	0.3
	Baden-Württemberg	1,067	0.0	0.0	100.0	5.4	0.0	0.0
	Baden-Württemberg	1,485	0.0	0.0	96.7	4.6	5.5	0.8
	Baden-Württemberg	4,405	0.0	0.0	93.8	2.0	5.9	1.3
	Baden-Württemberg	14,133	3.9	0.0	91.8	5.8	8.0	0.5
Germany	Saxony	884	0.1	1.4	96.6	0.0	3.5	0.0
Ireland	Ireland	190,520	2.0	0.3	88.7	0.0	10.0	0.7
Italy	Abruzzo	10,096	0.7	0.0	95.5	0.0	6.5	0.5
	Basilicata	11,790	1.1	0.4	87.0	0.0	10.1	0.3
	Basilicata	11,790	1.1	0.0	88.1	0.4	9.7	0.0
	Basilicata	10,097	0.9	0.1	88.4	0.4	17.7	0.8
	Basilicata	10,097	0.9	0.0	94.0	0.2	9.4	0.1
	Basilicata	46,297	1.8	0.0	81.4	0.0	36.0	0.9
	Basilicata	10,096	1.1	0.0	87.4	0.2	11.1	0.6
	Basilicata	14,197	0.1	0.0	88.8	0.4	11.8	0.5
	Basilicata	1,045	3.9	0.0	73.0	1.9	17.5	1.4
	Basilicata	591	2.3	0.0	74.0	0.0	7.2	0.0
	Basilicata	23,896	1.0	0.0	86.0	0.3	10.1	0.7
	Basilicata	10,097	1.0	0.0	89.9	0.1	14.4	0.5
	Basilicata	23,897	0.2	0.0	88.1	0.0	13.8	0.5
	Basilicata	10,097	1.4	0.0	87.8	0.1	10.1	0.5
Netherlands	Limburg	20,977	2.1	0.0	77.5	4.0	20.7	1.1
	Limburg	18,844	2.8	0.0	84.4	0.0	16.4	0.7
	Limburg	17,788	0.3	0.0	85.0	0.1	17.6	1.8
	Limburg	45,231	0.7	0.0	84.0	0.1	15.0	0.6
	Limburg	14,708	1.1	0.0	86.0	0.1	15.4	0.4
	Limburg	14,518	1.5	0.2	87.5	0.8	13.7	1.7

- Pediatric cancers
- Haematologic rare neoplasms
- Sarcomas
- Rare thoracic cancers
- Neuroendocrine tumours
- Head & neck cancers
- Central nervous system tumours
- Rare female genital cancers
- Rare urological and male genital tumours
- Endocrine gland tumours
- Digestive rare cancers
- Rare skin cancers & non-cutaneous melanoma

Rationale of the rare cancer list: a consensus paper from the Joint Action on Rare Cancers (JARC) of the European Union (EU)

Paolo G Casali,¹ Annalisa Trama²

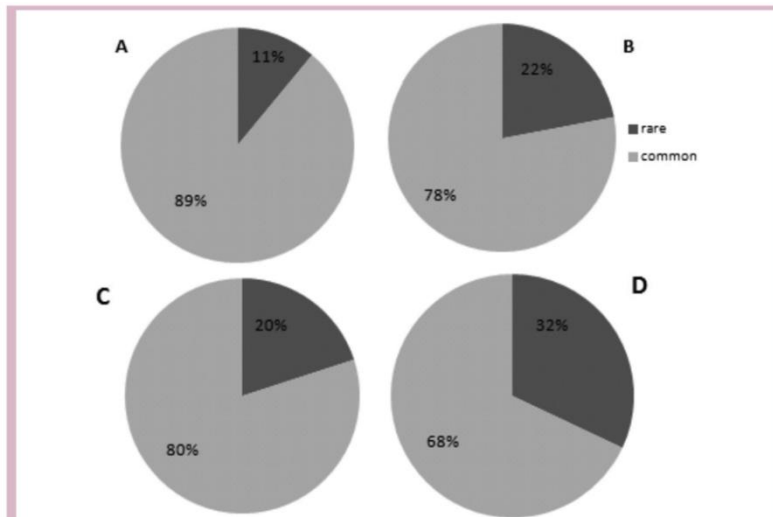


Figure 1 Percentage of rare and common cancers based on: the incidence rate of tier 1 cancer entities (A); incidence rate of tier 2 cancer entities (B); prevalence of tier 1 cancer entities (C); prevalence of tier 2 cancer entities (D).

Background The Surveillance of Rare Cancers in Europe (RARECARE) project proposed a definition and a list of rare cancers. The Joint Action on Rare Cancers (JARC), launched by the European Union and involving 18 member states and 34 partners, promoted a wide consensus effort to review the list.

Patients and methods A group of experts was set up, including scientific societies, member state representatives of JARC, representatives of the European Reference Networks dedicated to rare cancers and rare cancer patient advocates. The definition and the list of rare clinical entities, based on the incidence data provided by two European projects (RARECARE and RARECAREnet), were rediscussed through a consensus meeting of the expert panel.

Results By consensus, it was reiterated that the best criterion for a definition of rare cancers is incidence, rather than prevalence. By consensus, the experts slightly modified the composition of the tiers of rare cancers, according to the definition based on an incidence threshold <6/100 000/year, and grouped all rare cancers within 12 families of rare cancers. Even when defined conservatively this way, rare cancers are not rare collectively, since they correspond to 10%–20% of all cancer cases.

Conclusions The list of rare cancers reviewed by JARC should be viewed as a tool in the fight against rare cancers and rare diseases. It may help to appreciate that rare cancers are cancers and rare diseases at the same time, combining issues and difficulties of both. We hope that refinements to the list and a wider understanding of its implications may contribute to increase awareness of problems posed by rare cancers and to improve quality of care in a large group of patients with cancer, who may be discriminated against just because of the low frequency of their diseases.

RARE CANCER AGENDA 2030

Ten Recommendations from the EU Joint Action on Rare Cancers

1. Rare cancers are the rare diseases of oncology
2. Rare cancers should be monitored
3. Health systems should exploit networking
4. Medical education should exploit and serve healthcare networking
5. Research should be fostered by networking and should take into account an expected higher degree of uncertainty
6. Patient-physician shared clinical decision-making should be especially valued
7. Appropriate state-of-the-art instruments should be developed in rare cancer
8. Regulation on rare cancers should tolerate a higher degree of uncertainty
9. Policy strategies on rare cancers and sustainability of interventions should be based on networking
10. Rare cancer patients should be engaged

RARE CANCER AGENDA 2030

Ten Recommendations from the EU Joint Action on Rare Cancers



Brussels, 3.2.2021
COM(2021) 44 final

**COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN
PARLIAMENT AND THE COUNCIL**

Europe's Beating Cancer Plan

{SWD(2021) 13 final}

Recommendation		Potential synergy with other EU Research and Innovation Missions
1	Launch UNCAN.eu – a European Initiative to Understand Cancer	Missions on Soil health and food; Climate-neutral and smart cities; Adaptation to climate change including societal transformation
2	Develop an EU-wide research programme to identify (poly-) genic risk scores	Missions on Soil health and food; Climate-neutral and smart cities; Adaptation to climate change including societal transformation
3	Support the development and implementation of effective cancer prevention strategies and policies within Member States and the EU	Missions on Soil health and food; Climate-neutral and smart cities; Adaptation to climate change including societal transformation
4	Optimise existing screening programmes and develop novel approaches for screening and early detection	
5	Advance and implement personalised medicine approaches for all cancer patients in Europe	
6	Develop an EU-wide research programme on early diagnostic and minimally invasive treatment technologies	
7	Develop an EU-wide research programme and policy support to improve the quality of life of cancer patients and survivors, family members and carers, and all persons with an increased risk of cancer	Communication to citizens together with other Missions
8	Create a European Cancer Patient Digital Centre where	



	cancer patients and survivors can deposit and share their data for personalised care	
9	Achieve Cancer Health Equity in the EU across the continuum of the disease	
10	Set up a network of Comprehensive Cancer Infrastructures within and across all EU Member States to increase quality of research and care	
11	Childhood cancers and cancers in adolescents and young adults: cure more and cure better	
12	Accelerate innovation and implementation of new technologies and create Oncology-focused Living Labs to conquer cancer	
13	Transform cancer culture, communication and capacity building	Communication to citizens together with other Missions

Rare Cancers in All Policies

- *Conquering Cancer: Mission Possible*
- *Pharmaceutical Strategy for Europe*
- *Europe's Beating Cancer Plan*
- *EU Research and Innovation Programme (2021-27) and Horizon Europe*
- *EU4Health and the European Semester Programmes*
- *Patients' Rights in Cross-Border Healthcare*
- *A European Strategy for Data*
- *European Health Data Space*
- *Clinical Trials Regulation*
- *Proposal for a Regulation on Health Technology Assessment*
- *Orphan Medicinal Products and the Paediatric Regulations*
- *General Data Protection Regulation*



European Reference Networks

EpiCARE . BOND . CRANIO . ENDO . ERKNet . EYE . ERNICA . VASCERN . LUNG . RND . SKIN . EURACAN . GUARD-HEART . EuroBloodNet . eUROGEN . GENTURIS . ITHACA . MetabERN . PaedCan . RARE-LIVER . ReCONNET . EURO-NMD . TRANSPLANT-CHILD . RITA

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Brussels, 3.2.2021
COM(2021) 44 final

**COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN
PARLIAMENT AND THE COUNCIL**

Europe's Beating Cancer Plan

{SWD(2021) 13 final}

(a) Preparatory activities to establish 'National Comprehensive Cancer Centres and EU Network linking these Centres:

The aim of this joint action is to establish or upgrade Comprehensive Cancer Centres in Member States, and the creation of an EU network of the already existing and newly established Comprehensive Cancer Centres.

The EU Network of National Comprehensive Cancer Centres will support the implementation of quality-assured early detection, screening, diagnosis, treatment, support to cancer survivors, and training of the cancer workforce.

(b) Preparatory activities to establish an EU Network of Expertise on Cancers and Cancer Conditions:

The aim of this joint action is to establish the new EU Network of Expertise on Cancers and Cancer Conditions.

The EU Network will link with the existing four European Reference Networks for Rare Cancers and a group of new (possibly 5) EU Networks of Expertise to be funded under this action. This action will prepare the establishment of new EU Networks of Expertise, which will be supported to target specific, challenging cancer conditions, benefiting from cross-border cooperation and Union expertise. These conditions include metastatic diseases, comorbidities in cancer care, complex cancers with poor prognosis and specific conditions related to genomics in cancer care, integrative oncology, palliative care and survivorship.



«RARE CANCERS IN ALL POLICIES»

A RARE CANCERS EUROPE CALL TO ACTION

DATE: 28 SEPTEMBER
TIME: 13:00-15:30 CEST
LOCATION: VIRTUAL

Topic	Speaker	Organization	Time
PART 1: PERSPECTIVES ON THE EU POLITICAL AGENDA			13:00-14:05
<i>Moderated by Paolo G. Casali</i>			
Welcome and presentation of RCE's Call to Action: "Rare Cancers in All Policies"	Paolo G. Casali	Rare Cancers Europe Chair (RCE) European Society for Medical Oncology (ESMO)	13:00-13:10
European Commission's perspective	Martin Dorazil	DG SANTE, European Commission	13:10-13:20
European Parliament's perspective	Dolors Montserrat MEP Cristian Silviu Busoi MEP	European Parliament, Spain European Parliament, Romania	13:20-13:30
Regulatory perspective	Antonella Baron	European Medicines Agency (EMA)	13:30-13:40
Haematological community's perspective	Elizabeth Macintyre	European Hematology Association (EHA)	13:40-13:50
Paediatric community's perspective	Carmelo Rizzari	European Society for Paediatric Oncology (SIOPe)	13:50-14:00
Wrap-up	Paolo G. Casali	Rare Cancers Europe Chair (RCE) European Society for Medical Oncology (ESMO)	14:00-14:05
BREAK			10 MINUTES
PART 2: TOWN HALL: RARE CANCERS SHOULD NOT BE OVERLOOKED FROM THE EU POLITICAL AGENDA			14:15-15:15
<i>Moderated by Paolo G. Casali & Kathy Oliver</i>			
European Parliament's perspective	Bartosz Arlukowicz MEP Peter Liese MEP Cyrus Engerer MEP	European Parliament, Poland European Parliament, Germany European Parliament, Malta	14:15-14:30
European Reference Networks' perspective	Jean-Yves Blay Ruth Ladenstein Pierre Fenaux Nicoline Hoogerbrugge	ERN EURACAN, Rare Adult Solid Cancers ERN PaedCan, Paediatric Cancers ERN EuroBloodNet, Rare Haematological Diseases ERN GENTURIS, Genetic Tumour Risk Syndromes	14:30-14:50
Patient Advocates' perspective	Kathy Oliver Anita Kienesberger Jan Geissler (tbc) Rita Magenheimer	ePAG Representative for ERN EURACAN, RCE Steering Committee Member ePAG Representative for ERN PaedCan ePAG Representative for ERN EuroBloodNet ePAG Representative for ERN GENTURIS	14:50-15:10
Industry perspective	Ivana Cattaneo	Industry Representative, RCE Steering Committee	15:10-15:15
DISCUSSION AND Q&A			15 MINUTES
Conclusion and closing remarks	Paolo G. Casali	Rare Cancers Europe Chair (RCE) European Society for Medical Oncology (ESMO)	15:30



Thank you

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