RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates
January 2021
On-line training programme

The new EU Agenda on Cancer and the role of the European Reference Network EURACAN

J-Y Blay

EUROPEAN REFERENCE NETWORKS

European Reference Networks

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.

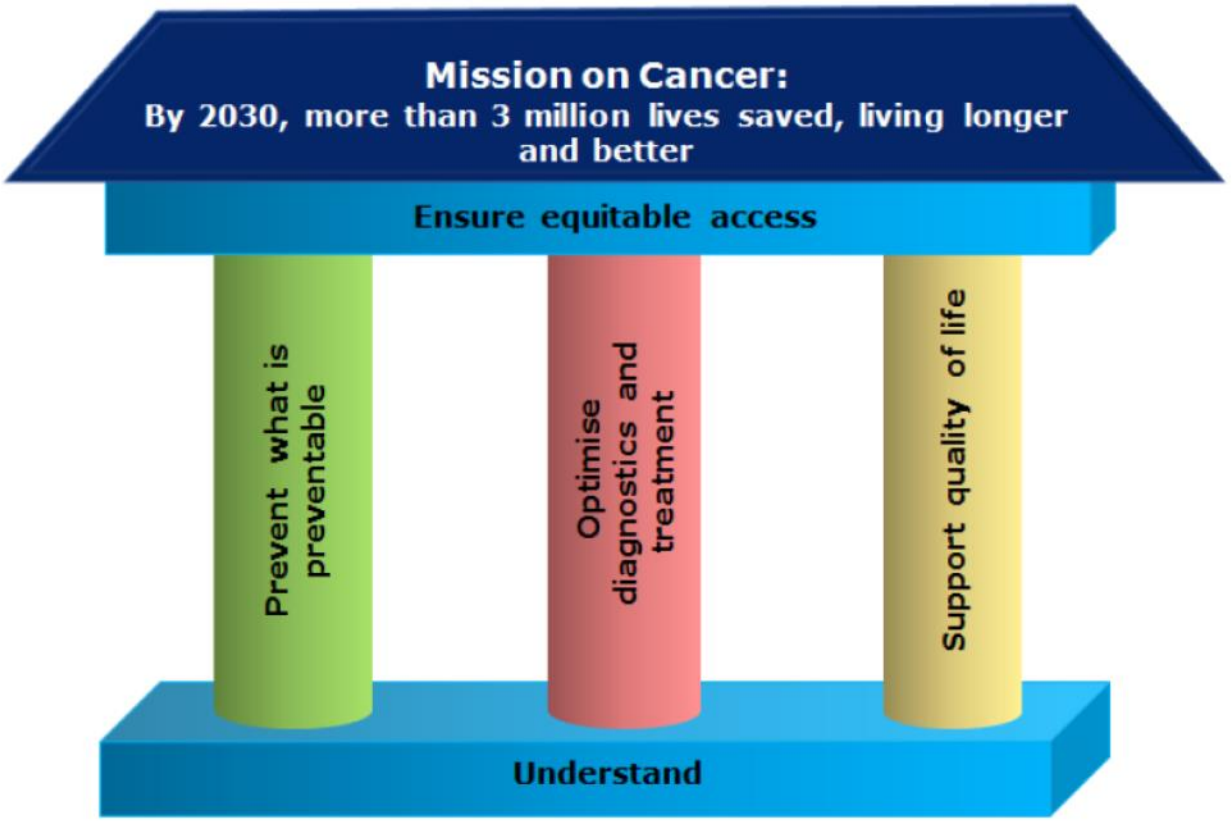
European Reference Network
for rare or low prevalence complex diseases

Network
Adult Cancers
(ERN EURACAN)

EURACAN
Rare Adult Solid Cancers

Co-funded by the EU


European Commission
CONQUERING CANCER:
MISSION POSSIBLE
Interim report of the Mission Board for Cancer
Independent Expert Report
Research and Innovation


Mission on Cancer:
By 2030, more than 3 million lives saved, living longer and better
Ensure equitable access
Prevent what is preventable
Optimise diagnostics and treatment
Support quality of life
Understand

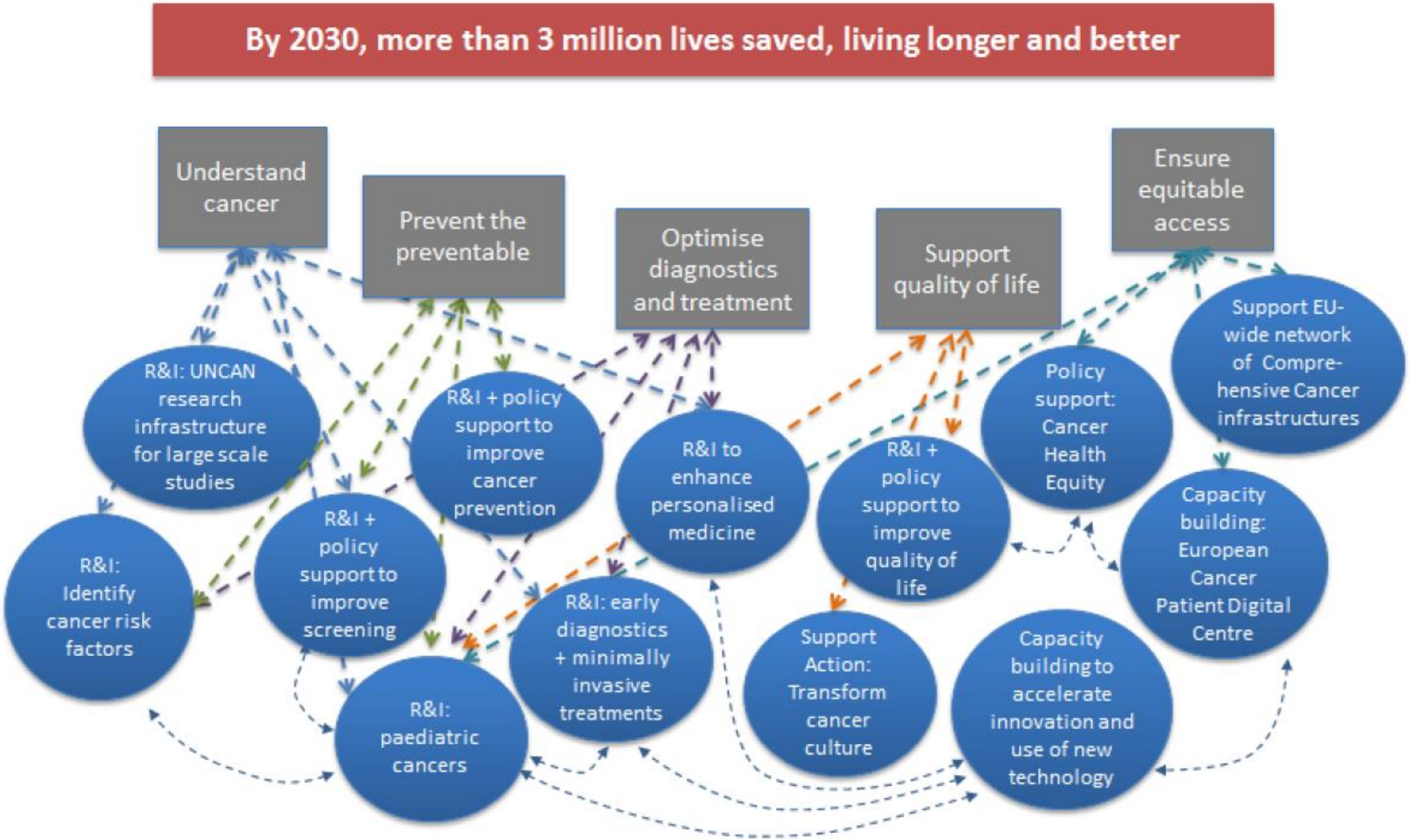


Figure 2. Relationships between Mission's goal, areas of action and recommended actions

☞Recommendation 10: Set up a network of Comprehensive Cancer Infrastructures within and across all EU Member States to increase quality of research and care

EURACAN

TARGERTED RACs

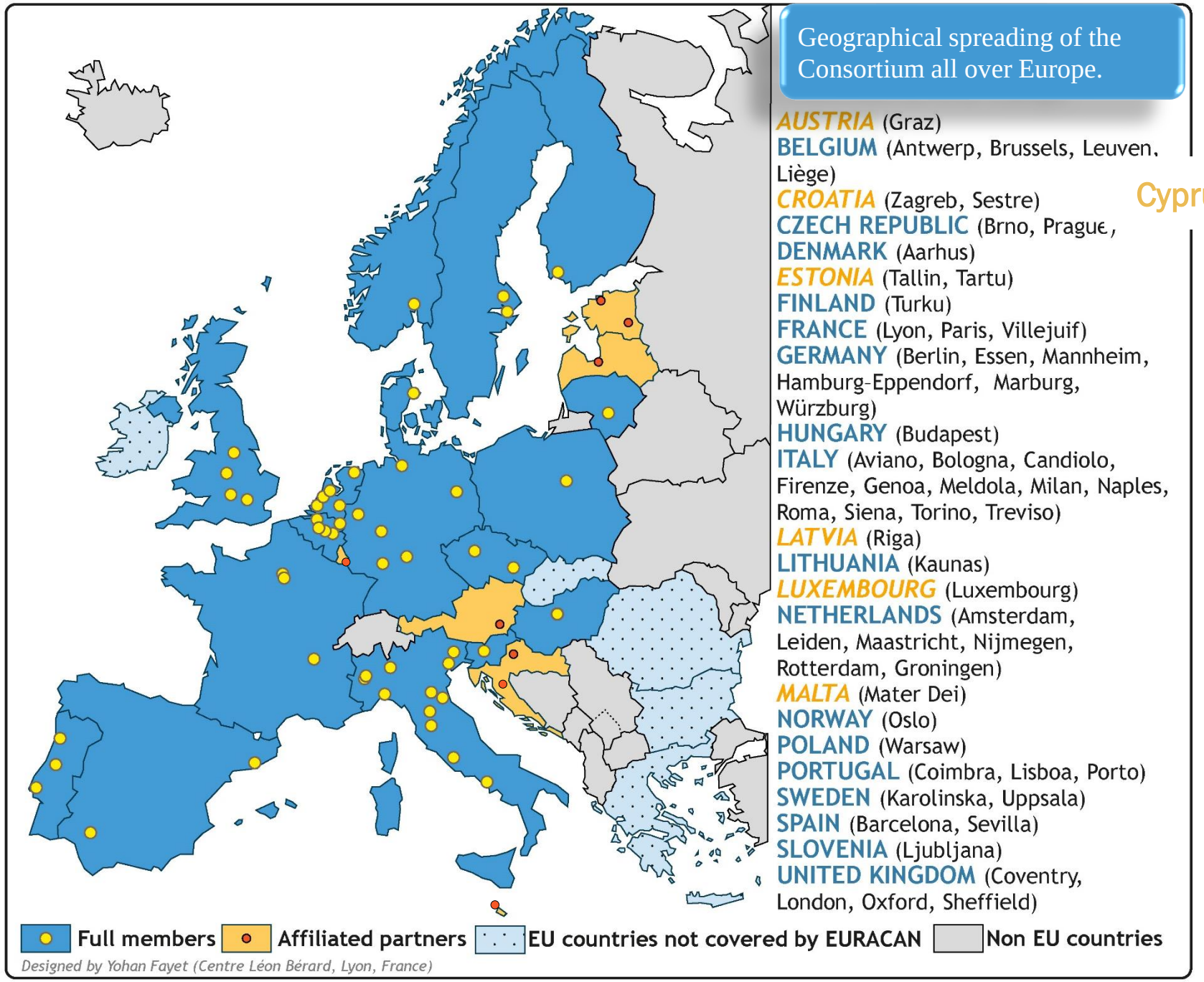
- Connective tissue
- Female genital organs and placenta
- Male genital organs, and of the urinary tract
- Neuroendocrine system
- Digestive tract
- Endocrine organs
- Head and neck
- Thorax
- Skin and eye melanoma
- Brain, spinal cords

SUB-THEMATIC AREAS

2017
- 66 full members accross 17 Member states

2020
- 9 APS accross 7 Member States

2021
42 new members



ASSOCIATE PARTNERS

AFFILIATED PARTNERS

Associated National Centres approved

Austria

- Centre for bone and soft tissue tumors – Graz

Croatia

- University Hospital centre - Zagreb
- Sestre University Hospital centre - Zagreb

Cyprus

- Bank of Cyprus oncology centre in collaboration with the Karaiskakio Foundation

Estonia

- North Estonia Medical Centre
- University Hospital - Taru

Latvia

- East clinical University Hospital - Riga

National Coordination hub approved

Luxembourg -Hospital Centre

Malta - Mater dei Hospital -

Member state code	Town	Candidate Name	DOMAIN(S) APPROVED BY THE BoN
BE	Brussels	Cliniques universitaires Saint-Luc ASBL	G1.1 G2.2 G5.2 G9.1 G10
	Ghent	Ghent University Hospital	G1 G2.2 G3.1 G6.1 G9.2
CZ	Prague	Thomayer Hospital	G3.1
	Prague	The institute for the Care of Mother and Child	G2.1
DE	Berlin	Helios Klinikum Berlin-Buch	G1.1 G1.2
	Munich	Comprehensive Cancer Center München	G1.1 G1.2 G2.1 G2.2 G3.1 G4 G5.1 G5.2 G5.3 G6.1 G6.2 G7 G8.1 G8.2 G9.1 G9.2
ES	Barcelone	Hospital Universitari Vall d'Hebron	G1.1 G1.2
	Madrid	General University Hospital Gregorio Marañon	G1.1 G1.2
	Madrid	Hospital Universitario Clínico san Carlos	G1.1 G2
FI	Helsinki	HUS University Hospital, Hospital District of Helsinki and Uusimaa	G1.1 G1.2 G2.2 G3.1 G6.1 G6.2 G7 G8.1 G8.2 G9.1 G9.2
FR	Pessac	CHU HAUT LEVEQUE _PESSAC	G4
	Bordeaux	CHU HOPITAL SAINT ANDRE _BORDEAUX	G10
	Bordeaux	Institut Bergonié	G1.1 G1.2 G2.1 G2.2
	Lille	Centre Oscar Lambret	G1.1 G1.2 G2.1
	Lille	CHU de Lille	G8.2 G9.2
	Marseille	Institut Paoli Calmettes	G4
	Marseille	Assistance Publique-Hôpitaux de Marseille	G7 G10

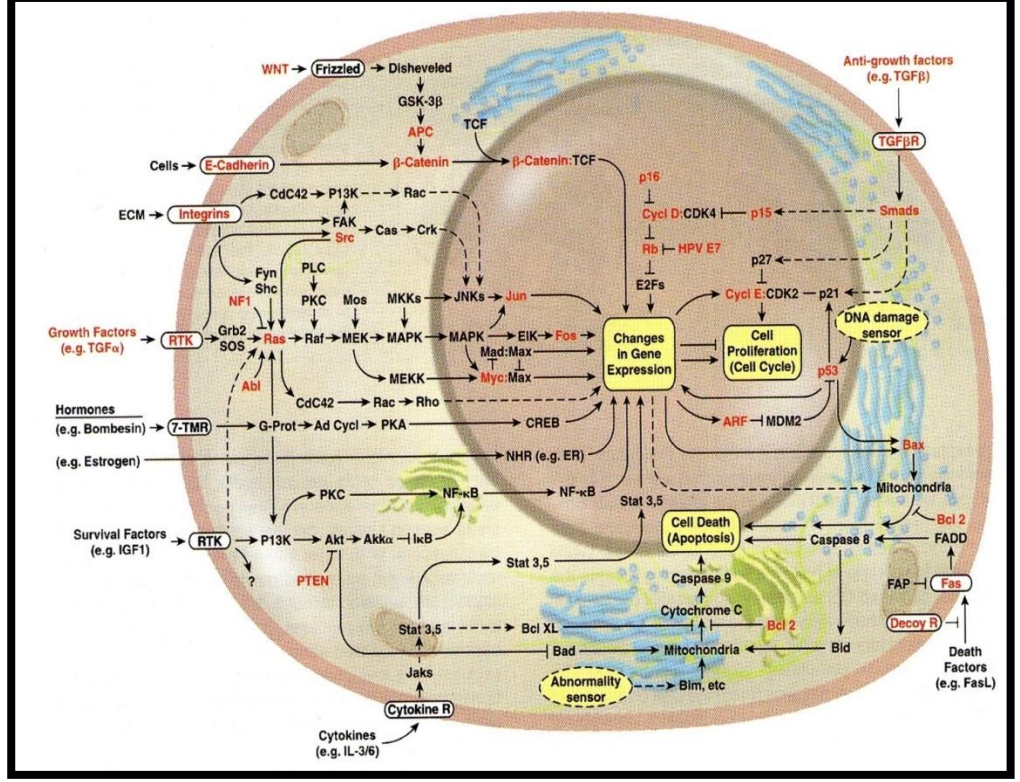
Member state code	Town	Candidate Name	DOMAIN(S) APPROVED BY THE BoN
GE	Athens	General hospital og Athens Laiko	G4
IE	Dublin	National Neuroendocrine Tumour Service, St. Vincent's University Hospital,	G4
IT	Alessandria	Azienda Ospedaliera SS Antonio e Biagio e Cesare Arrigo	G8.2
	Bari	IRCCS Istituto Tumori Giovanni Paolo II, Bar	G1.2
	Brescia	Spedali Civili di Brescia	OK G6.2 G7 G10
	Milan	Istituto Europeo di Oncologia	G1.2 G2.2 G3.1 G4 G6.1 G8.1 G8.2
	Milan	Istituto Auxologico Italiano - Istituto di Ricovero e Cura a Carattere Scientifico	G6.1
	Padova VIO	Veneto Institute of Oncology- IRCCS	G1.2 G3.1 G10
	Padova AOP	Azienda Ospedaliera di Padova	G1.1 G4 G5.3 G7 G8
	Palerme	AOUP "Paolo Giaccone"	G1.2
	Pavia	CNAO Centro Nazionale di Adroterapia Oncologica, National Center for Oncological Hadrontherapy	Ok G1.1 G1.2 G7
	Pise	Azienda Ospedaliera Universitaria Pisana	G1.1 G1.2 G6.1
	Rome Unicamp	Policlinico Universitario Campus Bio-Medico di Roma	G1.1 G1.2
	Verone	AOUI di Verona	G4

Member state code	Town	Candidate Name	DOMAIN(S) APPROVED BY THE BoN
LT	Vilnius	Vilniaus universiteto ligoninės Santariškių klinikos	G5
NL	Utrecht	University Medical Center Utrecht	G7
PL	Gliwice	Sklodowska-Curie National Research Institute of Oncology Gliwice Branch	G6.1
	Katowice	Uniwersyteckie Centrum Kliniczne im. prof. K. Gibińskiego Śląskiego	G4
PT	Porto	Instituto Português de Oncologia do Porto Francisco Gentil, EPE	G1.2 STS
RO	Cluj-Napoca	Institutul Oncologic "Prof. dr. Ion Chiricuță" Cluj-Napoca	G2.2
SE	Gothenberg	Sahlgrenska Universitetssjukhuset	G1.1 G1.2 G6.2

☞Recommendation 1: Launch UNCAN.eu – a European Initiative to Understand Cancer

Despite tremendous progress in deciphering the genetic and biological basis of cancer, our understanding of the molecular processes at the cancer cell level and the interactions of the tumour and its host is still very limited. This holds in particular for cancers for which understanding is lacking and rare cancers. The potential for increasing our understanding in this area is demonstrated by the significant benefit obtained through targeted therapies and host immune activation against some tumours. Recent technological developments and European collaborations provide an excellent opportunity for realising this potential through obtaining a comprehensive and dynamic view of how certain cancers initiate, develop and spread in the context of the host.

This requires a new level of investment in innovative research, including high-potential/high-risk projects. Therefore, the Mission Board proposes a Europe-wide platform, UNCAN.eu, utilising relevant research infrastructure and investing in the development of new models and technologies interrogating the interactions of cancers and their host. UNCAN.eu would encompass relevant stakeholders and enable integration of innovative models and technologies with longitudinal patient data, samples and biomarkers for identification and translation to patients. UNCAN.eu would provide breakthroughs in understanding how cancers initiate, develop and spread in the context of the host and thereby provide a basis for saving millions of European citizens' lives in synergy with actions related to recommendations 2-6 and 11-12 of this Draft Mission outline as well as actions related to the Europe's Beating Cancer Plan and other EU Research and Innovation Missions (see Annex I).



Sciencexpress Research Art

The Consensus Coding Sequences of Human Breast and Colorectal Cancers

Tobias Sjöblom,[1]* Siân Jones,[1]* Laura D. Wood,[1]* D. Williams Parsons,[1]* Jimmy Lin,[1] Thomas Barber,[1] Diana Ma
Rebecca J. Leary,[1] Janine Ptak,[1] Natalie Silliman,[1] Steve Szabo,[1] Phillip Buckhaults,[2] Christopher Farrell,[2] Paul Mee
D. Markowitz,[3] Joseph Willis,[4] Dawn Dawson,[4] James K. V. Willson,[5] Adi F. Gazdar,[6] James Hartigan,[7] Lec
Liu,[8] Giovanni Parmigiani,[9] Ben Ho Park,[10] Kurtis E. Bachman,[11] Nickolas Papadopoulos,[1] Bert Vogelstein,[1]
Kinzler,[1]† Victor E. Velculescu[1]†

Comprehensive genomic characte defines human glioblastoma genes and core pathways

The Cancer Genome Atlas Research Network*

Vol 455|23 October 2008|doi:10.1038/nature07385

Mutational landscape and significance across 12 major cancer types

Cyriac Kandoth[1]*, Michael D. McLellan[1]*, Fabio Vandin[2], Kai Ye[1,3], Beifang Niu[1], Charles Lu[1], Mingchao Xie[1], Qunyuan Zhang[1,3], Joshua F. McMichael[1], Matthew A. Wyczalkowski[1], Mark D. M. Leiserson[2], Christopher A. Miller[1], John S. Welch[4,5], Matthew J. Walter[4,5], Michael C. Wendl[1,3,6], Timothy J. Ley[1,3,4,5], Richard K. Wilson[1,3,5], Benjamin J. Raphael[2] & Li Ding[1,3,4,5]

TP53 loss creates therapeutic vulnerability in colorectal cancer

Yunhua Liu[1], Xinna Zhang[2,3], Cecil Han[1], Guohui Wan[1], Xingxu Huang[4], Cristina Ivan[2,3], Dahai Jiang[2,3], Cristian Rodriguez-Aguayo[3,5], Gabriel Lopez-Berestein[3,5], Pulivarthi H. Rao[6], Dipen M. Maru[7], Andreas Pahl[8], Xiaoming He[9], Anil K. Sood[1,2,3], Lee M. Ellis[10], Jan Anderl[8] & Xiongbin Lu[1,3]

Comprehensive molecular characterization of gastric adenocarcinoma

The Cancer Genome Atlas Research Network*

Ordered incidences of sarcomas and connective tissue tumors in NETSARC & published clinical trials

Histotypes	Total (2013-2016)	Incidence /10e6/year	Ph III	RPh II	Ph II
	25172	**95,104**			
Incidence >10/10e6/year					
Fibroblastic and myofibroblastic tumours	5274	19,977			
Gastrointestinal stromal tumors (GIST).	3272	12,394			
Adipocytic tumours	3247	12,299			
ALL Undifferentiated sarcoma	2717	10,292			
ALL smooth muscle tumours	2679	10,148			
Incidence <10/10e6/year					
Undifferentiated pleomorphic sarcoma	1556	5,894			
All vascular tumor	1520	5,758			
Liposarcoma – dedifferentiated	1345	5,095			
Desmoid fibromatosis	1339	5,072			
Atypical lipomatous tumour/WDLPS	1266	4,795			
Uterine sarcoma	1138	4,311			
Leiomyosarcoma	1094	4,144			
Dermatofibrosarcoma Protuberans	1040	3,939			
Leiomyosarcoma -differentiated	945	3,580			
Solitary fibrous tumour (all)	925	3,504			
Undifferentiated sarcoma NOS	853	3,231			
Sarcoma NOS	844	3,197			
Solitary fibrous tumor	751	2,845			
Angiosarcoma	728	2,758			
Kaposi sarcoma	663	2,511			
Conventional osteosarcoma	661	2,504			
Myxofibrosarcoma	630	2,386			
Ewing sarcoma	614	2,326			
ALL Rhabdomyosarcoma	608	2,303			
Chondrosarcoma NOS	572	2,167			
Uterine leiomyosarcoma	545	2,064			
Leiomyosarcoma – poorly differentiated	516	1,955			
ALL Synovial sarcoma	442	1,674			
Atypical fibroxanthoma	429	1,625			
Myxoid or round cell liposarcoma	409	1,549			
Liposarcoma - myxoid	355	1,345			
All GCTB	330	1,250			
Giant cell tumour of bone	324	1,227			
Undifferentiated spindle cell sarcoma	308	1,167			
ALL Peripheral nerve sheath tumours	286	1,083			

Histotypes	Total (2013-2016)	Incidence /10e6/year	Ph III	RPh II	Ph II
		95,104			
Incidence <1/10e6/year					
Synovial sarcoma - monophasic	244	0,924			
Endometrial stromal sarcoma, low grade	238	0,902			
Embryonal RMS	179	0,678			
High risk SFT	174	0,659			
Malignant peripheral nerve sheath tumour	173	0,655			
Other histological subtypes of bone sarcoma	171	0,648			
Osteosarcoma NOS	168	0,636			
Conventional chordoma	164	0,621			
Adenosarcoma	156	0,591			
All undifferentiated sarcoma of bone	152	0,576			
Inflammatory myofibroblastic Tumour	145	0,549			
Pleomorphic RMS	144	0,545			
Undifferentiated uterine sarcoma	141	0,534			
Liposarcoma - pleomorphic	139	0,527			
Phyllode sarcoma	138	0,523			
Embryonal rhabdomyosarcoma usual type	137	0,519			
Low grade fibromyxoid sarcoma	136	0,515			
Alveolar RMS	123	0,466			
Smooth muscle tumour of undetermined ma	122	0,462			
Epithelioid sarcoma	120	0,455			
Central chondrosarcoma, grades 2 and 3	117	0,443			
So-called fibrohistiocytic tumours	106	0,402			
Epithelioid hemangioEndothelioma	100	0,379			
Epithelioid sarcoma	98	0,371			
Extraskeletal osteosarcoma	96	0,364			
Myoepithelioma, myoepithelial carcinoma,	96	0,364			
Dedifferentiated chondrosarcoma	93	0,352			
RMS NOS	88	0,333			
Myoepithelioma	85	0,322			
Central atypical cartilaginous tumour / chon	76	0,288			
Clear cell sarcoma of soft tissue	71	0,269			
Giant cell tumour of soft tissue	70	0,265			
Synovial sarcoma - biphasic	70	0,265			
Undifferentiated pleomorphic sarcoma of bo	69	0,261			
PECOMA - NOS	67	0,254			
Extraskeletal myxoid chondrosarcoma	58	0,220			
Round cell sarcoma with EWSR1-non-ETS fus	56	0,212			
Liposarcoma - round cell	54	0,205			
Aneurysmal bone cyst	53	0,201			
Desmoplastic small round cell tumour	52	0,197			
Tumors of intermediate malignancy NOS ALL	52	0,197			
Chondroblastoma	52	0,197			
Extrarenal rhabdoid tumour	51	0,193			
Intimal sarcoma	46	0,174			
Angiomatoid fibrous histiocytoma	43	0,163			
Sclerosing epithelioid fibrosarcoma	41	0,155			
Endometrial stromal sarcoma - high-grade	41	0,155			
All parosteal osteosarcoma	40	0,152			
Leiomyosarcoma of bone	40	0,152			
Spindle cell RMS	39	0,148			
Peripheral chondrosarcoma	39	0,148			
Synovial sarcoma - poorly Differentiated	37	0,140			
Malignant rhabdoid tumor	36	0,136			
Ossifying fibromyxoid Tumour	32	0,121			
Alveolar soft part sarcoma	31	0,117			
Mesenchymal chondrosarcoma	31	0,117			
Osteoblastoma	31	0,117			
Plexiform fibrohistiocytic tumors	29	0,110			
Embryonal rhabdomyosarcoma spindle cell	29	0,110			
Angiosarcoma of bone	29	0,110			
Adult fibrosarcoma	28	0,106			
Parosteal osteosarcoma	27	0,102			

Histotypes	Total (2013-2016)	Incidence /10e6/year	Ph III	RPh II	Ph II
Incidence <0.1/10e6/year					
Osteoblastoma-like osteosarcoma					
Chondromyxoid fibroma	26	0,098			
Undifferentiated spindle cell sarcoma	26	0,098			
Periosteal chondrosarcoma	25	0,095			
High-grade surface osteosarcoma	25	0,095			
Myxoinflammatory Fibroblastic Sarcoma	23	0,087			
Embryonal RMS sarcoma - botryoid type	23	0,087			
Undifferentiated epithelioid sarcoma	22	0,083			
Langerhans cell histiocytosis	20	0,076			
Malignant PECOMA	19	0,072			
Low grade central osteosarcoma (ALL)	19	0,072			
Adamantinoma	19	0,072			
UTROSC	17	0,064			
Endometrial stromal nodule	16	0,061			
Telangiectasic osteosarcoma	16	0,061			
SMARCA4-deficient thoracic sarcoma	15	0,057			
Clear cell chondrosarcoma	14	0,053			
Low grade Myofibroblastic Sarcoma	13	0,049			
Dedifferentiated parosteal osteosarcoma	13	0,049			
Dedifferentiated low grade central osteosar	12	0,045			
Giant cell Fibroblastoma	11	0,042			
Sclerosing RMS	11	0,042			
CIC-rearranged sarcoma	11	0,042			
Infantile fibrosarcoma	10	0,038			
Pericytic (perivascular) tumours	10	0,038			
Malignant Triton tumour	10	0,038			
Retiform hemangio-endothelioma	9	0,034			
Ectomesenchymoma : Malignant mesenchyn	9	0,034			
Malignant granular cell Tumour	9	0,034			
Haemosiderotic fibrolipomatous tumour	9	0,034			
Synovial sarcoma of bone	9	0,034			
RMS of bone	9	0,034			
Lipofibromatosis	8	0,030			
Sarcoma with BCOR genetic alterations	7	0,027			
Low-grade central osteosarcoma	7	0,027			
Pseudomyogenic hemangioendothelioma	6	0,023			
Intermediate vascular tumours	6	0,023			
MPNST - epithelioid type	6	0,023			
Mixed tumour	6	0,023			
Desmoplastic fibroma of bone	6	0,023			
Malignant/dedifferentiated GCTB	6	0,023			
BCOR Sarcoma of bone	6	0,023			
Intermediate fibrohistiocytic tumors	5	0,019			
Adult spindle cell RMS	5	0,019			
Phosphaturic mesenchymal tumour	5	0,019			
Low grade sinonasal sarcoma	5	0,019			
Periosteal osteosarcoma	5	0,019			
Kaposiform hemangioendothelioma	4	0,015			
Small cell osteosarcoma	4	0,015			
Myoepithelioma of bone	4	0,015			
Liposarcoma of bone	4	0,015			
Composite hemangioendothelioma	3	0,011			
Malignant perineurioma	3	0,011			
Adult fibrosarcoma of bone	3	0,011			
Liposarcoma - mixed type	2	0,008			
Malignant tenosynovial giant cell tumors	2	0,008			
Metastatic leiomyoma	2	0,008			
Malignant myoepithelial Tumour	2	0,008			
Osteoblastoma-like osteosarcoma	2	0,008			
Dedifferentiated chordoma	2	0,008			
Lipomatous spindle cell/pleomorphic tum	1	0,004			
Papillary intralymphatic angioendotheliom	1	0,004			
Melanotic neuroectodermal tumour of infan	1	0,004			
Osteogenic tumor of uncertain prognosis	1	0,004			
Fibro-osseous tumour of bone NOS	1	0,004			
Undifferentiated epithelioid sarcoma	1	0,004			

☞Recommendation 2: Develop an EU-wide research programme to identify (poly-)genic risk scores

This action aims to assess the individual cancer risk with refined algorithms based on newly identified polygenic risk scores (PRS). Based on an increased understanding of individual cancer risks, education activities and counselling could be improved.

☞Recommendation 3: Support the development and implementation of effective cancer prevention strategies and policies within Member States and the EU

Preventing cancers calls for effective policy underpinned by excellent research. The Mission Board proposes to establish a research programme to identify effective cancer prevention strategies and methods to provide up-to-date knowledge to EU institutions and countries for designing and implementing effective cancer prevention measures at EU- and national level, tailored to local needs and conditions. Initial areas of research would focus on alcohol, food and sugar sweetened beverages and tobacco consumption, as well as commercial determinants[28] of health. These would be supplemented with research on exposures to workplace carcinogens, including emerging causes of cancer, air pollution, interactions of behavioural risk factors and comorbidities, as well as prevention strategies along the entire cancer continuum.

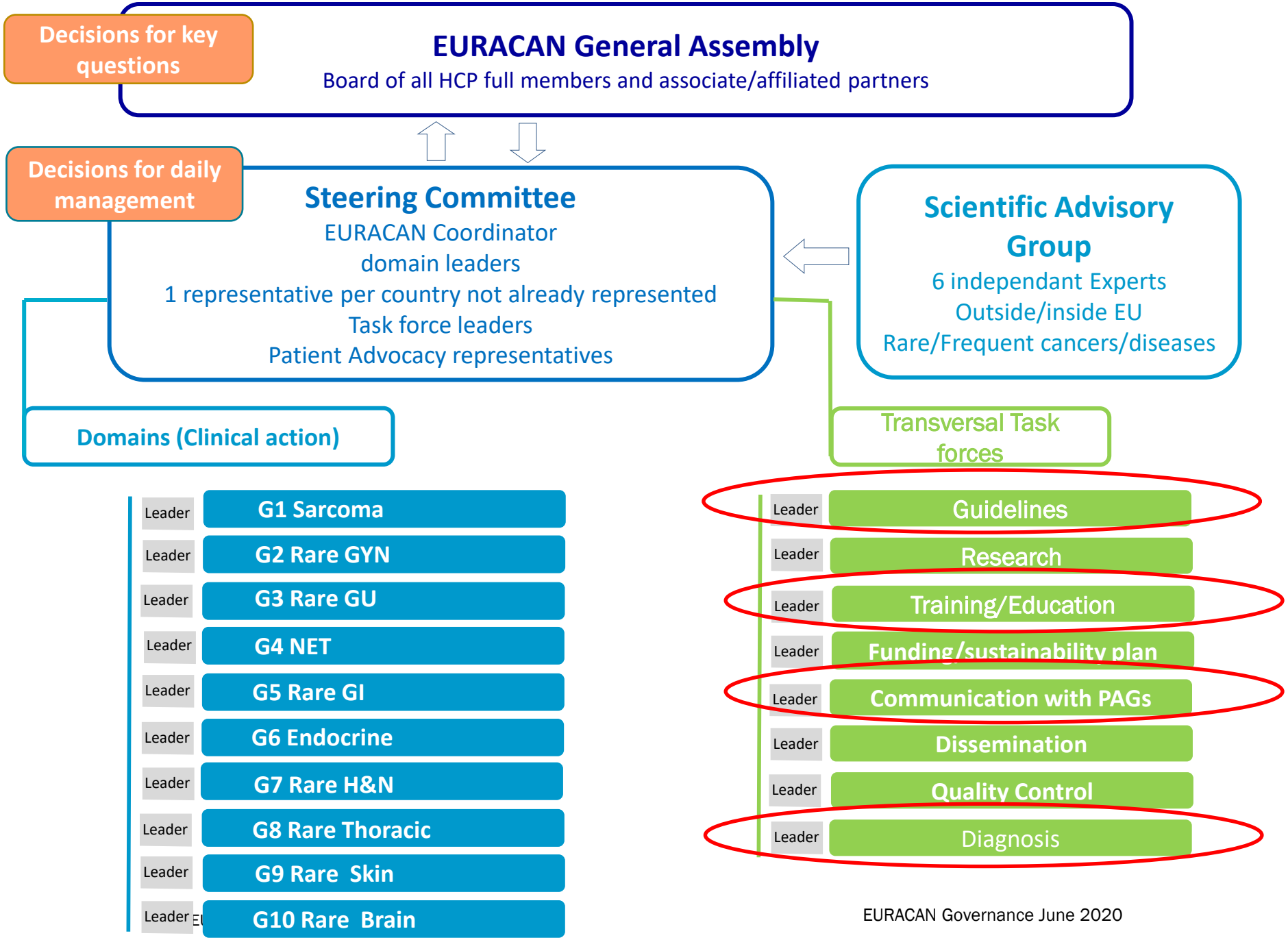
Prevention and understanding aetiology

- Not our first mission
- But an opportunity to do that on rare cancers through registries and biological studies
- Support from EJP RD needed!

☞**Recommendation 4: Optimise existing screening programmes and develop novel approaches for screening and early detection**

☞**Recommendation 6: Develop an EU-wide research programme on early diagnostic and minimally invasive treatment technologies**

GOVERNANCE



EURACAN Governance June 2020

GUIDELINES

2018 2019

Sarcomas, in collaboration with the ESMO, development of the **ESMO-EURACAN** guidelines: **Gastrointestinal stromal tumours**, **Soft tissue and visceral sarcomas**

ESMO-PaedCan-EURACAN Bone Sarcomas guidelines

Medulloblastomas: in collaboration with EANO, development of clinical practice guidelines for **diagnosis, treatment, and follow-up of post-pubertal and adult patients with medulloblastoma.**

Pleural Mesotheliomas : EURACAN/IASLC Proposals for Updating the Histologic Classification of : Towards a More Multidisciplinary Approach

Peritoneal malignancies: in collaboration with PSOGI & RENAPE development of guidelines on pseudomyxomas & peritoneal mesotheliomas

2020

In collaboration with the ESMO development of the following ESMO EURACAN guidelines are on-going:
Mesothelioma; Penile cancer; Biliary cancer; Testicular cancer; Eye melanoma, Merkel Cell carcinoma.

WEBSITE ON EURACAN CPGs

Rare cancer of connective tissue

Soft Tissue and Visceral | GIST | Bone sarcomas

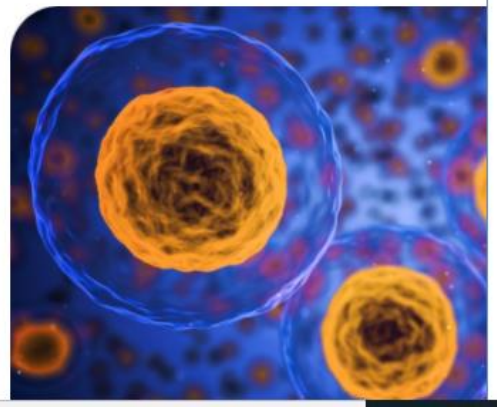
Soft tissue and visceral sarcomas: ESMO–EURACAN Clinical Practice Guidelines for diagnosis, treatment and follow-up

DOWNLOAD GUIDELINE

Introduction

Expert Center

MultiDisciplinary Team



These ESMO–EURACAN Clinical Practice Guidelines cover STSs (Soft Tissue sarcomas).

In general, the same principles apply to children and adults for these tumors.

- Multidisciplinary approach by sarcome expert in a Multi disciplinary Team is mandatory in all cases.
- Management of STS should be carried out in reference centres for sarcomas and/or within reference networks

see page on reference networks and centres

Referral of all patients with a lesion suspected to be a sarcoma would be recommended.

Patient's typology

PATIENTS' LEAFLETS

Domains also work on developping patient brochures on their respective diseases to be disseminated in centres accross Europe.

- **Endocrine tumours**
  - Refractory thyroïd
  - Adrenal cancers

- **Gynae tumours**:
  - Ovarian Sex Cord-Stromal Tumours (oSCST)
  - Gestational Trophoblastic Disease
  - Malignant ovarian Germ Cell tumors
  - Granulosa tumour
  - Rare Cervical cancers

- **Digestive tract**
  - Biliary tract
  - Peritoneal
  - Anal cancers

These brochures will be translated using both the e translation tool and a review will be performed by each member state in its own language

EDUCATION & TRAINING

In the framework of EURACAN and the JARC, ESO implemented new e-sessions on Rare Adult Solid Cancers on an annual basis with the ultimate goal to strengthen the educational coverage of a group of cancers which may be neglected in spite of their collective incidence

The European school of Oncology in collaboration with the University of Milan, has also launched a series of **Post-graduate Courses**for an international audience of clinical oncologists interested in advancing their knowledge and skills on rare adult solid cancers
***University post-graduate course* - clinical oncology**

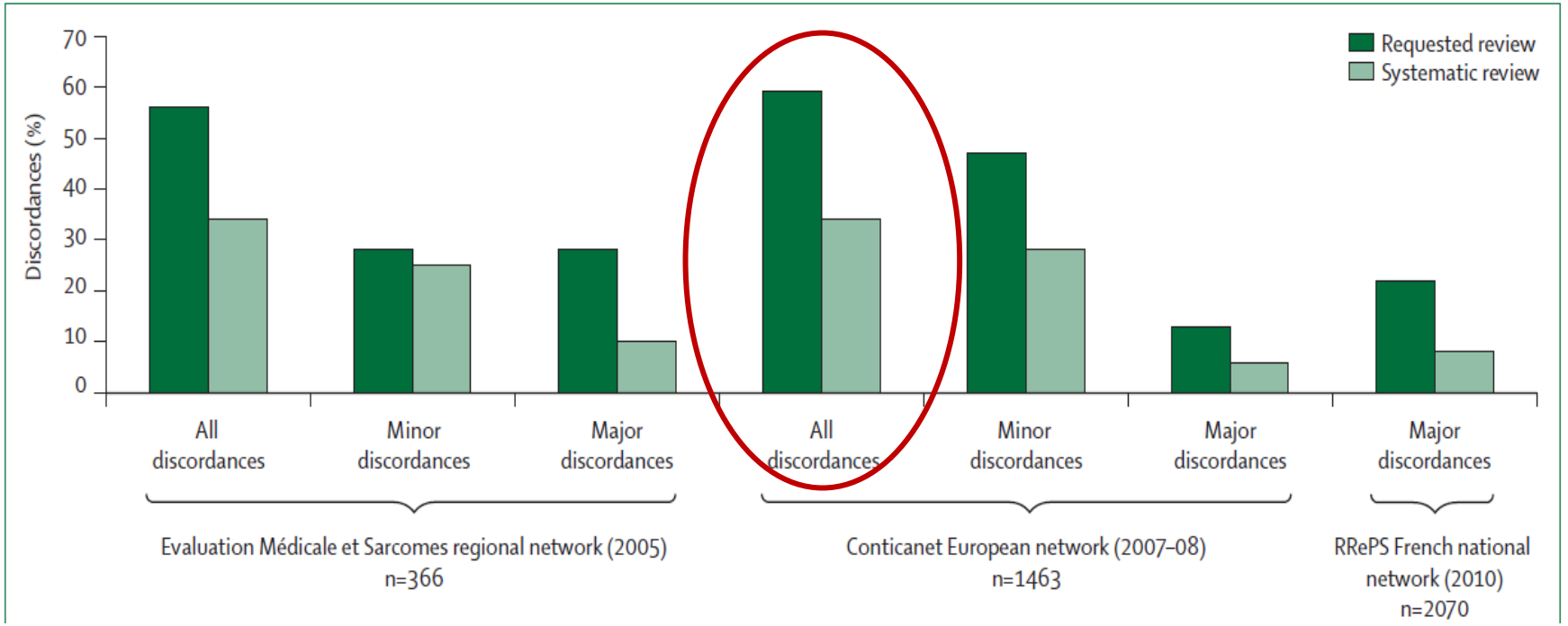
The video-recorded lessons of these two courses are available on the e-learning website www.eso.net

Preceptorships: clinical update on Rare Adult Solid Cancers

e-learning sessions (live)
The recorded sessions are available on www-e-eso.net

☞Recommendation 9: Achieve Cancer Health Equity in the EU across the continuum of the disease

Histological discordances



Histological reviews registered in 2010: 14% of major discordances (341 cases)

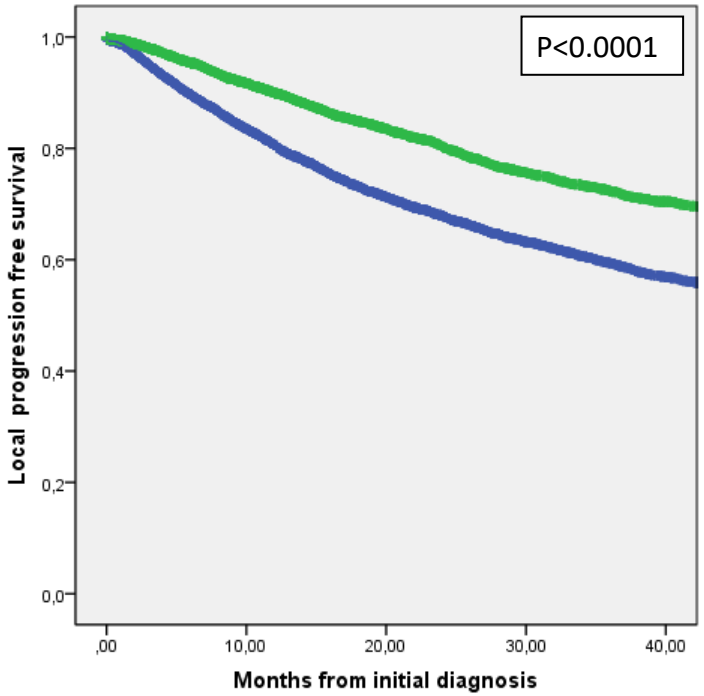
Cost of the treatments assessed for the initial diagnosis: €2,186,816 vs. final diagnosis: €1,060,174

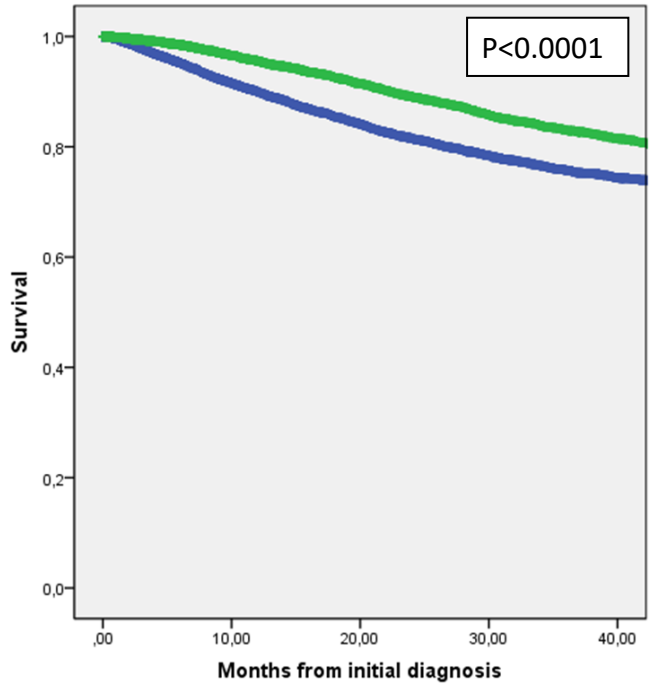
Histological reviews/molecular biology result in a cost saving of more than €1,000,000

Lionel Perrier, ISPOR 19th, Canada, June 2014

Healthcare system should ensure that accurate pathology is critical to good care. Histopathologists should be members of a quality assurance scheme which allows second opinions to be routine practice

LRFS & OS : incident patient population





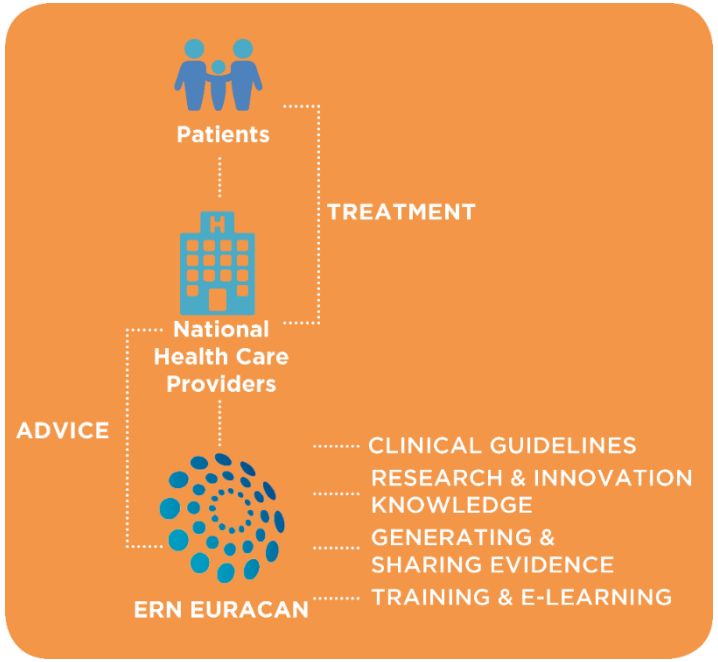
Operated
- **In NETSARC, N=9910 (38.5%)**
- **Outside NETSARC or no data, N=15901 (61.5%)**

Clinical Patient Management System (CPMS)

- **The Clinical Patient Management System (CPMS)** is the secure web-based application provided by the EC to support ERNs in the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders. https://cpms.ern-net.eu/login/

- Physicians can ask for their patient case to be reviewed by expert registered on the platform either by organizing 'virtual' advisory boards of medical specialists across different disciplines or by uploading patient clinical data, images or virtual slides to get a second opinion on a management or review of a diagnosis

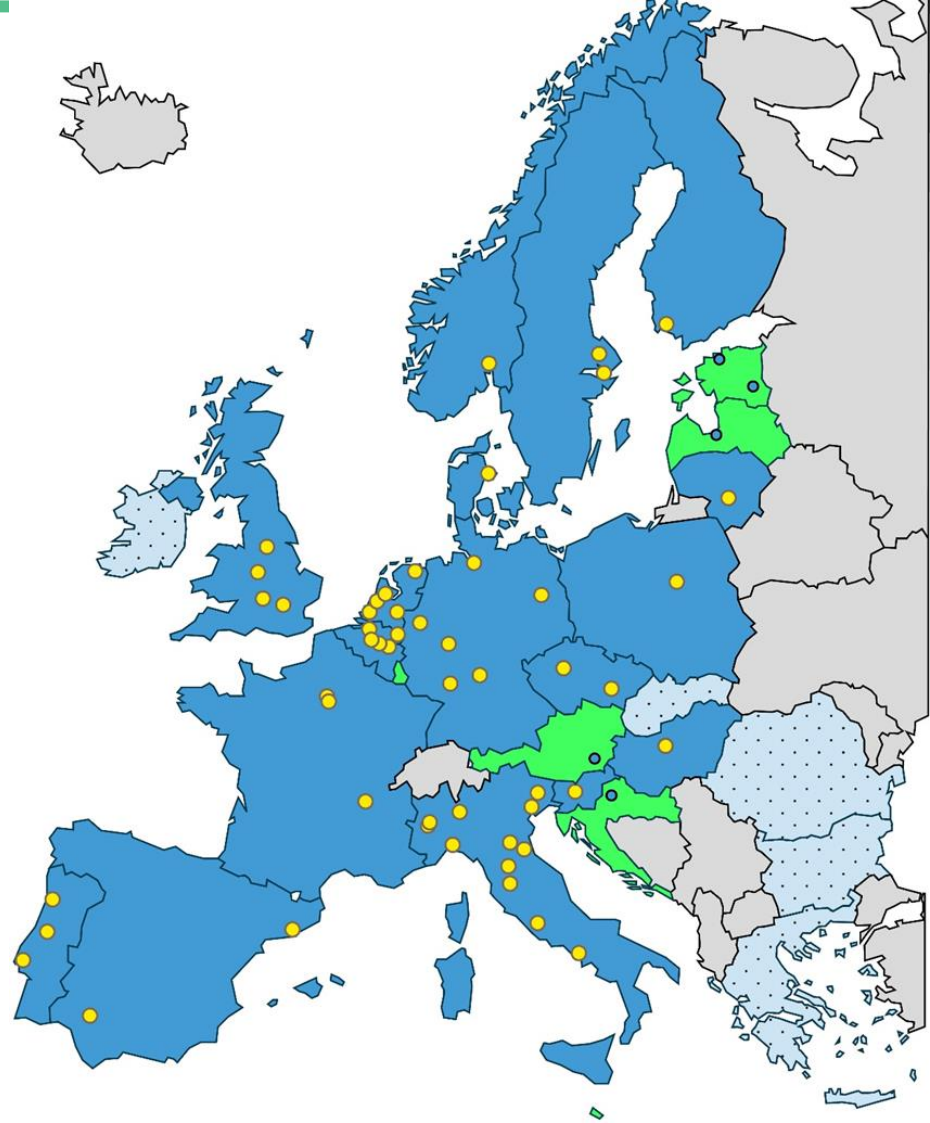
The goal is to have clinical and biological patient data to travel and not patients



ACCESS

- The CPMS/ERNs are not accessible directly to patient, however, with a patient's consent and in accordance with the rules of their national health system, a patient’s information can be uploaded on the platform and referred to the relevant ERN member by their healthcare provider.

- Physicians from ERNs
- Physicians from outside the network, from the EU/EEA can also access the CPMS as guests



EURACAN CPMS ACCESS PROCEDURE Http://137.74.172.63/euracan/decisiontree/home

Guide to the CPMS

Are you a **healthcare professional*** ?

Yes

No

*A healthcare professional is, according to the Article 3(f) of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare: 'a doctor of medicine, a nurse responsible for general care, a dental practitioner, a midwife or a pharmacist within the meaning of Directive 2005/36/EC, or another professional exercising activities in the healthcare sector which are restricted to a regulated profession, as defined in Article 3(1)(a) of Directive 2005/36/EC, or a person considered to be a health professional according to the legislation in the Member State of treatment'.

You are a healthcare professional

Let's see if there is a **national network covering the disease** you are concerned about in your country.

Please choose the country you are working in :

Austria	**France**	Malta	Sweden
Belgium	Germany	Netherlands	United Kingdom
Bulgaria	Greece	Norway	Another country
Croatia	Hungary	Poland	
Cyprus	Ireland	Portugal	
Czech Republic	Italy	Romania	
Denmark	Latvia	Slovak Republic	
Estonia	Lithuania	Slovenia	
Finland	Luxembourg	Spain	

You are working in France

Please choose the rare cancer you are concerned about.

- **Sarcoma** — Sarcoma
- **GU** — Male genital organs and urinary tract
- **GI** — Digestive tract
- **H & N** — Head and neck
- **Skin/eye melanoma** — Skin and eye melanoma
- **Gynae** — Female genital organs and placenta
- **NET** — Neuroendocrine system
- **Endo** — Endocrine
- **Thorax** — Thorax
- **Brain** — Brain and spinal cord

Rare cancer of connective tissue

Please contact **the following network** for the management of your patient.

NetSarc+

NetSarc is the French clinical reference network for soft tissue and visceral sarcomas, implemented in 2010 and approved by the INCa in 2019 (28 centers).

https://expertisesarcome.org/centres-experts-par-region/

CLCC Léon Bérard 28 rue Laennec
69373 LYON CEDEX 8 France

Jean-Yves BLAY (Coordinator)
+33478782757

European Reference Network
for rare or low prevalence complex diseases

STARTER

STarting an Adult Rare Tumour European Registry

European Reference Networks

European Reference Network
for rare or low prevalence complex diseases

Network Adult Cancers
(ERN EURACAN)

FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI

Annalisa Trama
annalisa.trama@istitutotumori.mi.it

Co-funded by the EU

STARTER (3 YEARS)

EURACAN REGISTRY

(WILL STAY…)

EURACAN Registry tumours included

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

EURACAN Registry health care providers involved

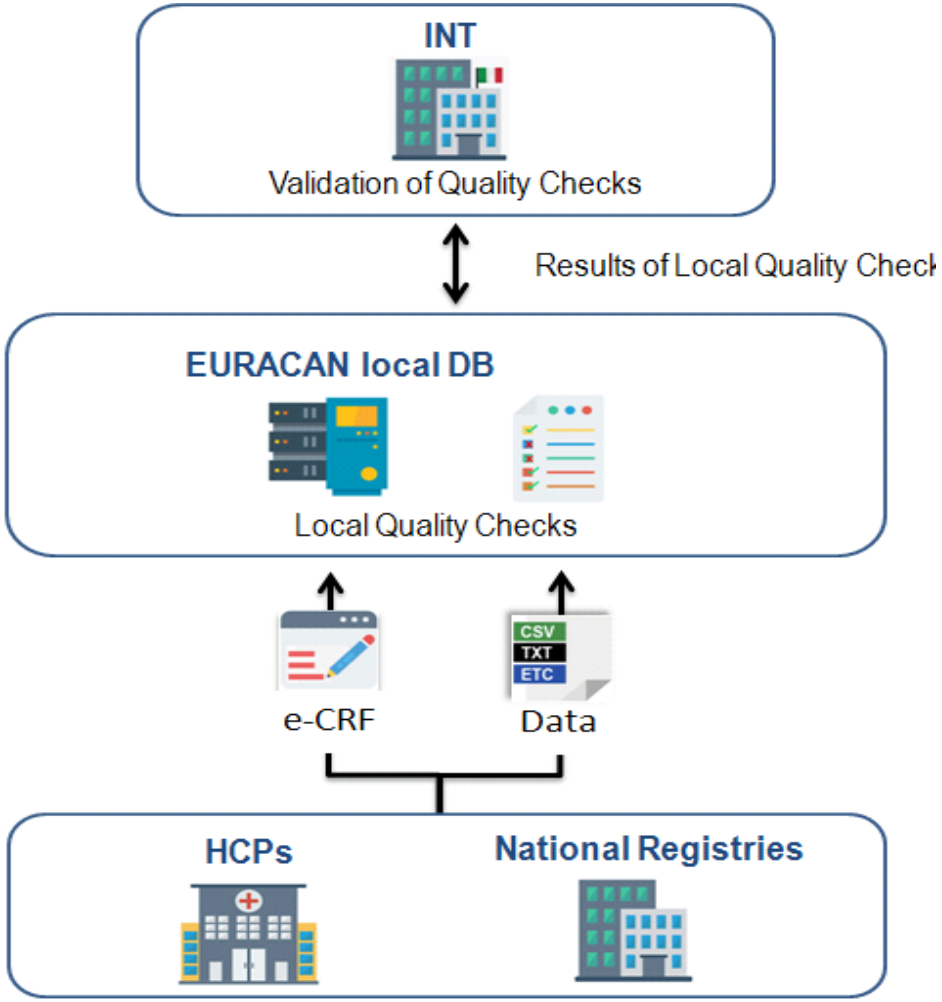
Open to Not EURACAN health care providers

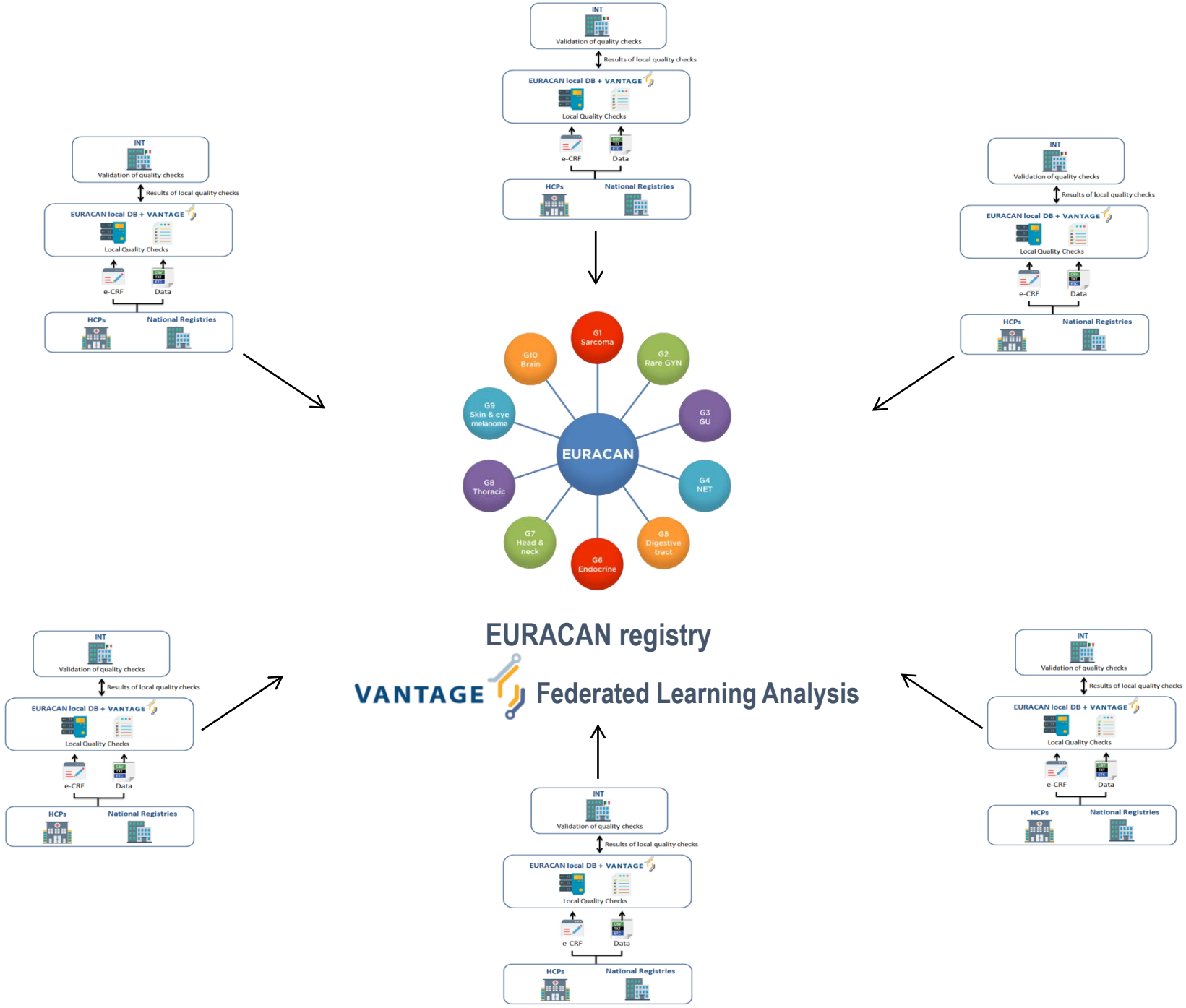
STARTER
STarting an Adult Rare Tumour European Registry

- Develop the IT infrastructure
- Define the rare cancer family in major need of a registry
- Discuss the objectives of the registry per each rare cancer family
- Address legal and ethical issues for data collection and data sharing
- Develop the EURACAN registry governance

EURACAN REGISTRY

Federated model




INT
Validation of quality checks
Results of local quality checks
EURACAN local DB + VANTAGE
Local Quality Checks
e-CRF
Data
HCPs
National Registries
G1 Sarcoma
G2 Rare GYN
G3 GU
G4 NET
G5 Digestive tract
G6 Endocrine
G7 Head & neck
G8 Thoracic
G9 Skin & eye melanoma
G10 Brain
EURACAN
EURACAN registry
VANTAGE
Federated Learning Analysis

☞Recommendation 5: Advance and implement personalised medicine approaches for all cancer patients in Europe

Personalised medicine offers the promise of maximally effective therapies with minimal harm, both for patients and society. While considerable efforts are being made (e.g. ERA PerMed[31], ICPerMed[32]), many cancer patients still do not benefit from personalised medicine approaches. This recommendation aims to advance, scale, implement and optimise current personalised medicine approaches for cancer, deepening our understanding of cancer complexity, i.e. the role of the host, the impact of the outer environment on cancer initiation, and the evolution of cancer over time, to increase the number of patients for whom effective personalised approaches can be found.

As increased precision in cancer management will rely on large datasets for

☞**Recommendation 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**

☞**Recommendation 8: Create a European Cancer Patient Digital Centre where cancer patients and survivors can deposit and share their data for personalised care**

Best treatment is key, post treatment & tertiary prevention should be in our focus

☞**Recommendation 11: Childhood cancers and cancers in adolescents and young adults: cure more and cure better**

☞**Recommendation 12: Accelerate innovation and implementation of new technologies and create Oncology-focused Living Labs to conquer cancer**

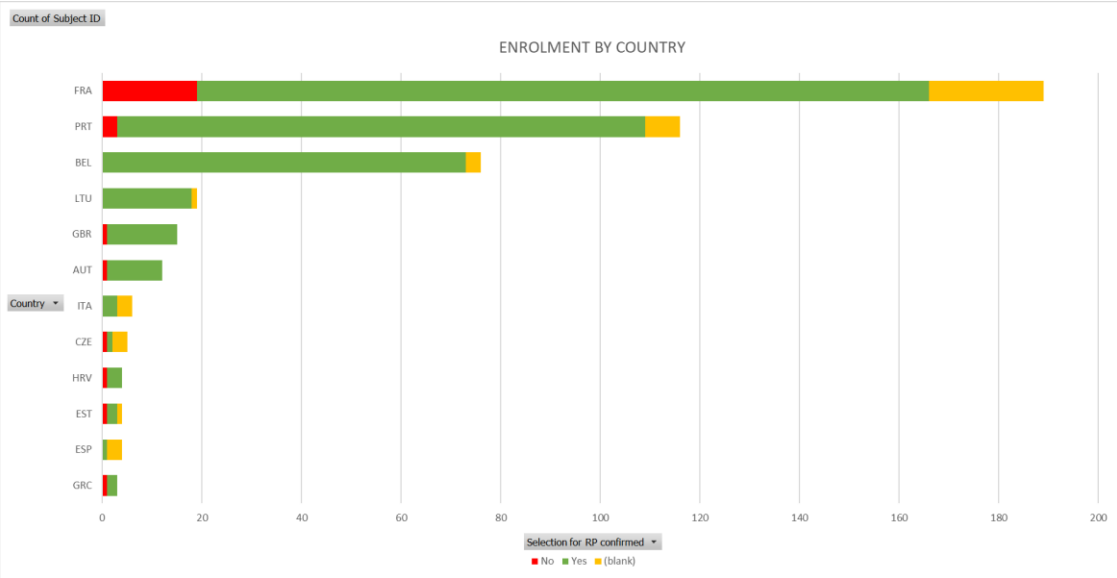
1843-ARCAGEN
STATUS EURACAN NETWORK 2020-10

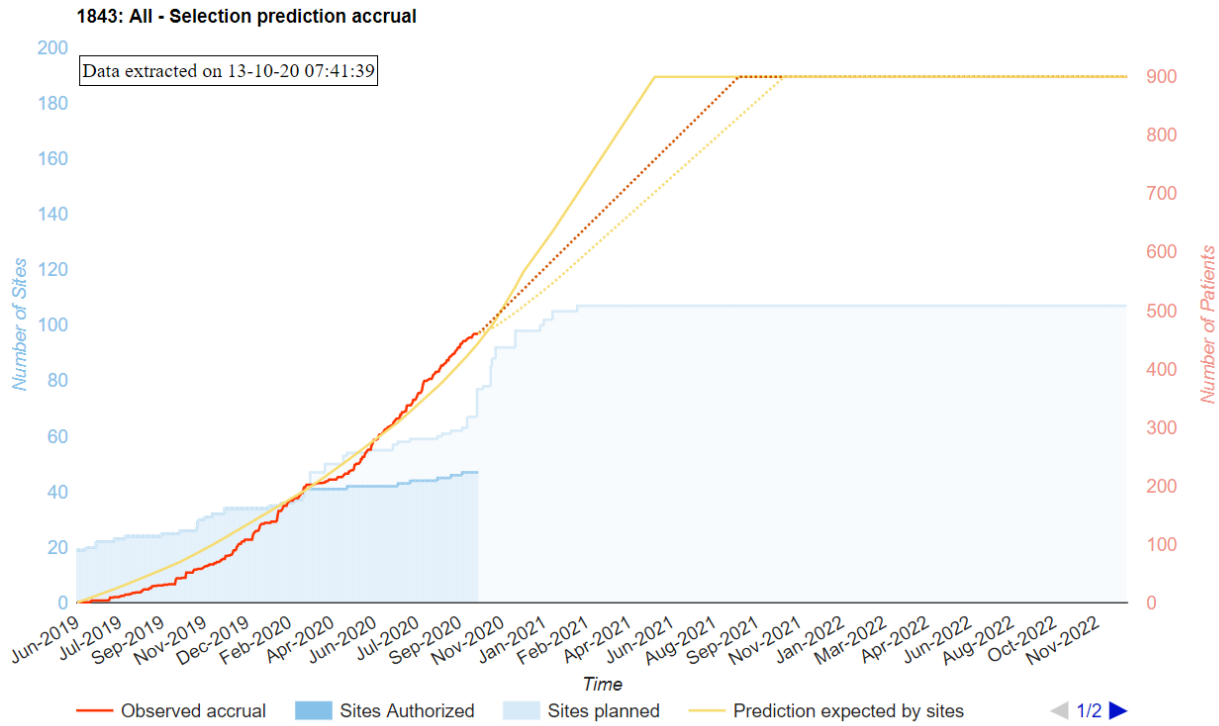
ARCAGEN RECRUITMENT STATUS

STATUS	08-Jan	30-Sep	Evolution
# of registered patients	99	453	358%
# of eligible patients	45	310	589%
# of Patients pending	50	112	124%
# of not eligible patients	8	31	288%

Registration per domain	Patient number (Prospect)	Patient number (Retrospect)
Domain 1- Sarcoma	6	41
Domain 2- Ovarian	35	9
Domain 3 - Rare GU	5	
Domain 4 - Neuroendocrine	43	
Domain 5 - GI	82	
Domain 6 - Endocrine	52	
Domain 7 - H&N	30	14
Domain 8 - Thoracic	26	13
Domain 9 - Skin & Uveal melanoma	6	
Domain 10 - CNS	5	
Multidomain	20	
Total	**310**	**77**

- ✓ **Recruitment from 28** investigators from **12** countries
- ✓ 40-50 patients / month since end of May

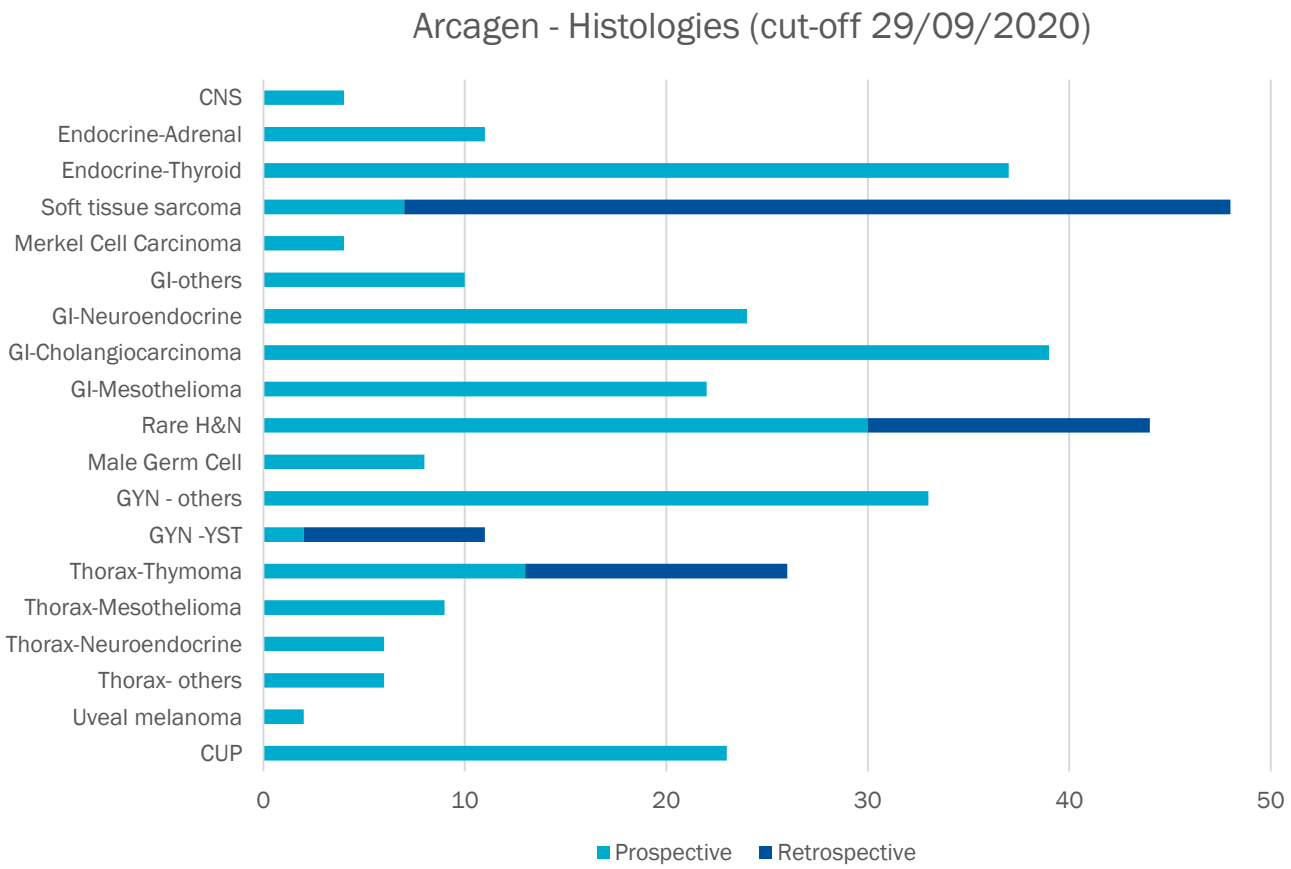




Molecular Reports

- Molecular reports generated: 301
  - F1 Liquid: 26%
  - F1 Heme: 2%
  - F1 CDx: 57%
- TAT: 3 to 5 weeks
- F1Liquid CDx to replace F1Liquid in Q4 2020

Cohort Review



- Upcoming Cohort adaptation:
  - Domain 1
  - Domain 2
  - Domain 4
  - Domain 5
  - Domain 10

  } Under discussion

- Protocol amendment targeted for Dec 2020

PUBLICATIONS - COMMUNICATION

- Publication on retrospective part:
  - Global publication submitted/in review - ESMO Open
  - Poster for ENA (24-25 Oct)
  - Specific GYN publication under preparation

- Communication on prospective part
  - Discussion with NCCJ (Japan), for possible collaboration around Arcagen,
  - A possibility could be to propose a co-analysis of some rare cancer subtypes common in Arcagen and Japanese cohort

- General communication plan - 2021

TRacKING

Real world European registry of rare actionable fusions

Collection of clinical data from cancer patients harboring an actionable fusions (NTRK and others)

↓

To describe the survival rate of this population in real-life practice, according to overall survival (OS)

CENTRE DE LUTTE CONTRE LE CANCER LEON BERARD

European Reference Network
for rare or low prevalence complex diseases
Network Adult Cancers (ERN EURACAN)

TRacKING

Real world European registry of rare actionable fusions

European Reference Networks

European Reference Network
for rare or low prevalence complex diseases

Network Adult Cancers (ERN EURACAN)

- At least 41 centers in 11 countries
- Up to 250-500 patients
- EHR data and quality of life questionnaire (QLQC30)
- 2 years inclusion - 2 years follow up
- Opening in Europe: Q1 2021

Regulatory submission in France

→ Feedback expected this month

→ Immediate opening of French centers

Contractualization with a CRO for regulatory submissions

Aixial: in charge of regulatory submission to ECs (in countries other than France)

➔ will contact center to obtain missing information for the submission (e.g. CV of the PI)

➔ is not in charge of establishing contracts. **Contracts will be established between participating centers and CLB**.

➔ **CLB remains your contact for all questions**

aixial
AN ALTEN COMPANY

Co-funded by the EU

TRacKING

Real world European registry of rare actionable fusions

Austria	2
Croatia	0
Cyprus	0
Czech republic	1
Denmark	1
Estonia	0
Finland	0
France	15
Germany	10
Hungary	0
Italy	7
Lithuania	0
Luxembourg	0
Malta	0
Netherlands	1
Norway	0
Poland	1
Portugal	0
Slovenia	1
Spain	1
Sweden	0
UK	1
TOTAL	41

If your did not receive the feasibility questionnaire or the newsletter, and/or if you would like to participate, please do not hesitate to contact us!

CONTACT

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Clinical Research Associate
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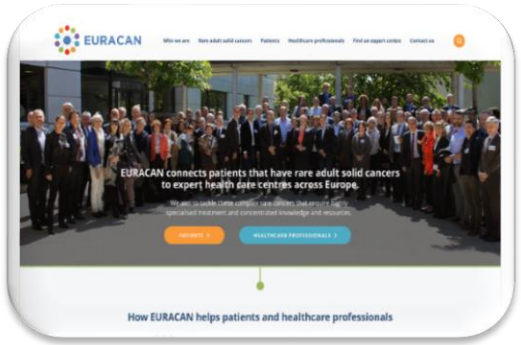
Thank you!

☞Recommendation 13: Transform cancer culture, communication and capacity building

COMMUNICATION & DISSEMINATION

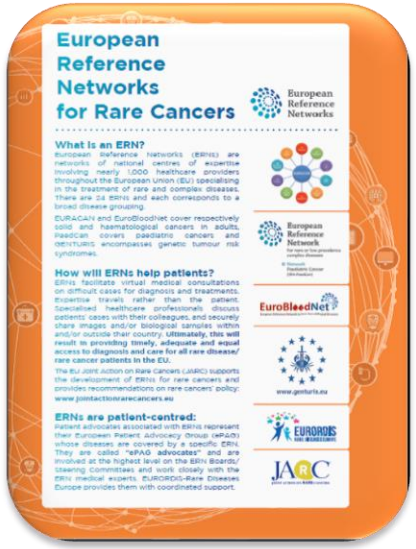
New EURACAN website



website Newsletter

ECP

ECP Newsletter



ONLINE EVENT

5TH ESO-ESMO-RCE
CLINICAL UPDATE ON RARE ADULT SOLID CANCERS

PRE-RECORDED SESSIONS:
from 1 December 2020

LIVE SESSIONS:
16-17 January 2021

Chairs: J.Y. Blay, FR - P.G. Casali, IT - R.A. Stahel,

REGISTRATION FOR THE EVENT IS FREE BUT MANDATORY.
FURTHER INFORMATION AVAILABLE AT WWW.ESO.NET AND WWW.E-ESO.NET

Held in collaboration with

Fondazione IRCCS Istituto Nazionale dei Tumori
Sistema Socio Sanitario Regione Lombardia

In partnership with

European Reference Network
for rare or low prevalence complex diseases
Network Adult Cancers (ERN EURACAN)

European Reference Networks

European Reference Network
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Conclusions

- ERN are key to the objectives of the mission cancer

- Prevention(s)
- In depth biological understanding of these cancers (genomics, immunology…)
- Early detection
- QoL
- Big data