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Shared data & Cancer registries

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Disclosures

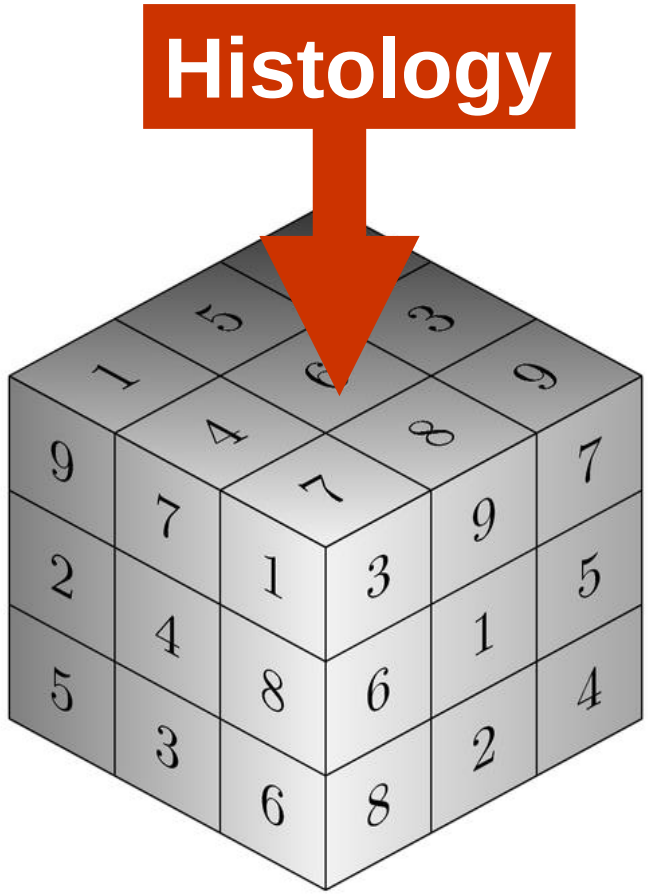
Company	Scientific advice	Scientific works	Symposia & oral communication
Abbvie	x	x	
Amgen	x	x	x
ARIAD	x	x	
AstraZeneca		x	x
Bayer	x	x	x
BMS	x	x	x
Deciphera	x	x	
DDB	x	x	
EISAI	x	x	x
Genomic Health		x	x
Gilead		x	x
GSK		x	x
INNATE PHARMA	X (member of the Supervisory committee)		
INCYTE		x	
IQVIA	x	x	x
Jansenn		x	x
LILLY		x	x
Merck Serono		x	x
MSD		x	x
Nanobiotix	x	x	
Novartis	x	x	x
Novex		x	x
Onxeo	x		
Pfizer		x	x
Pharmamar	x	x	
PRA		x	
Roche		x	x
Sanofi Aventis		x	x
Swedish Orphan		x	x
Takeda		x	
Toray		x	

Shared data & Cancer registries

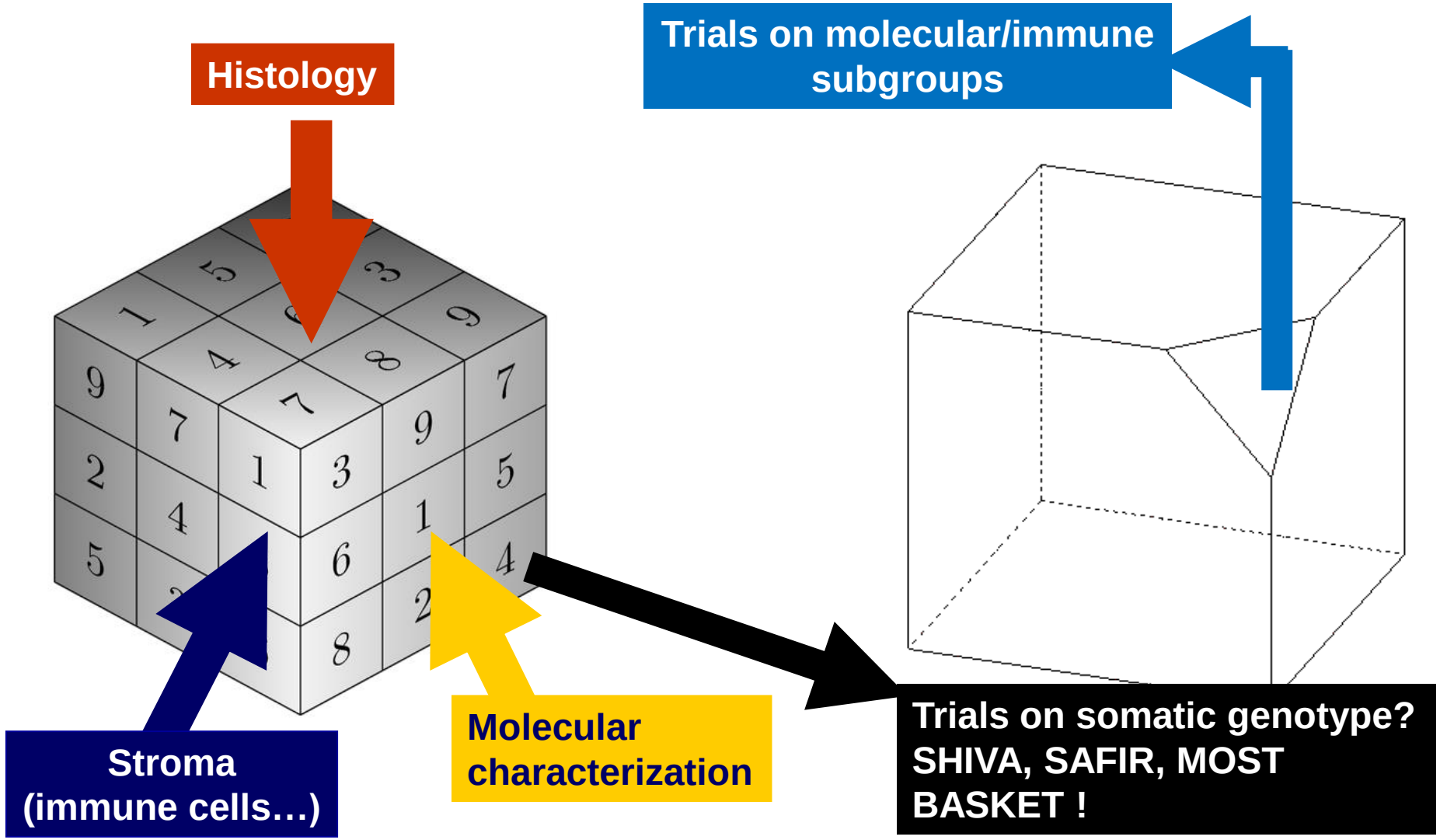
- The revolution of oncology : precision medicine vs biology based oncology (.. emerging rare cancers)

- Shared data & registries:
  - Diagnosis
  - Epidemiology
  - Optimal primary treatment is cheaper
  - Connecting patients and doctors
  - Academic clinical and translational research

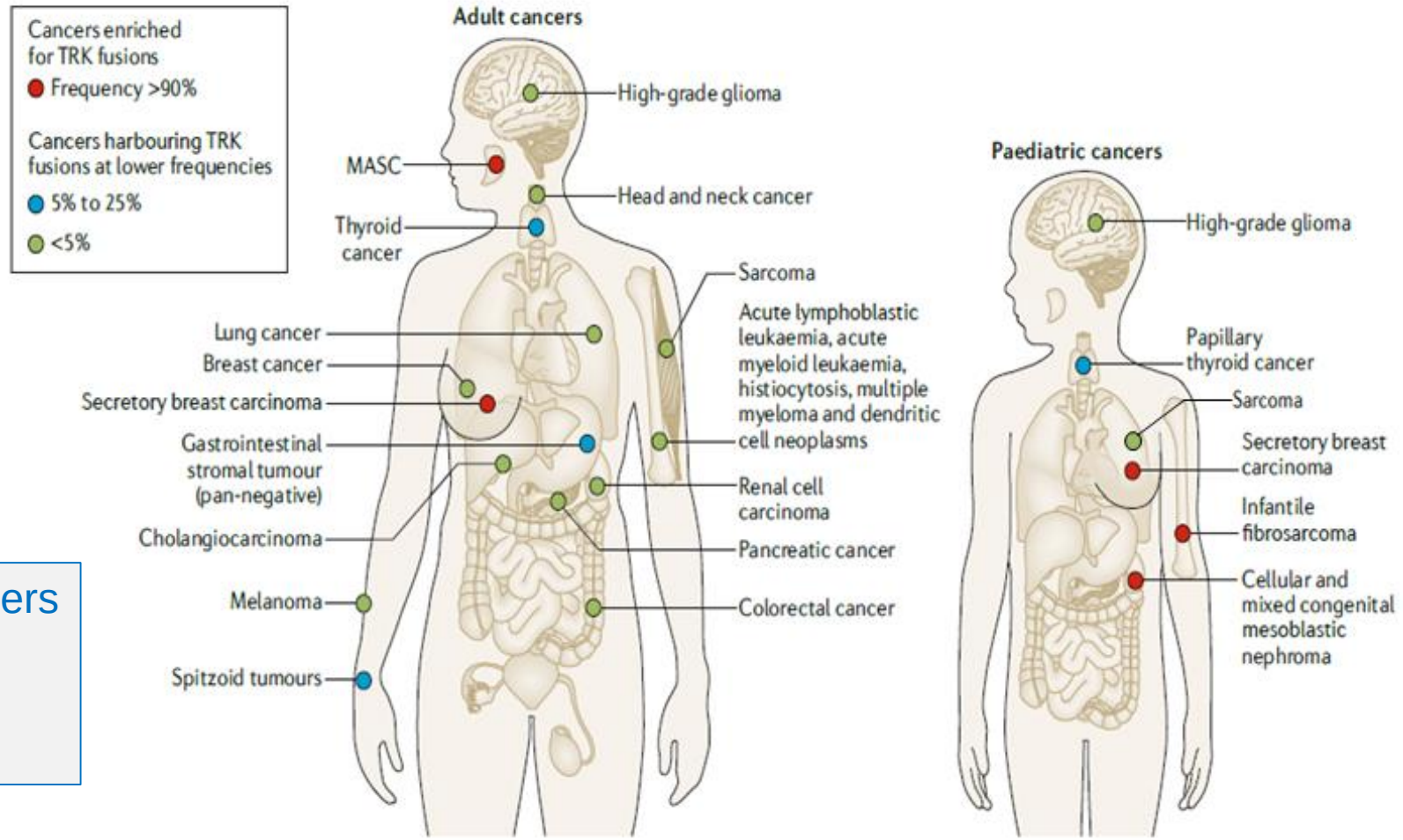
Nosology and treatment



Nosology & treatment 2021+



Example : NTRK fusions across cancers



0.5-1% of all cancers
9000/year in EU?
Diagnosis?
Treatment?

EURACAN : THE ERN FOR RARE ADULT SOLID CANCERS

Ten groups of rare cancers

- 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

20% of cancers
30% of the deaths due to cancer

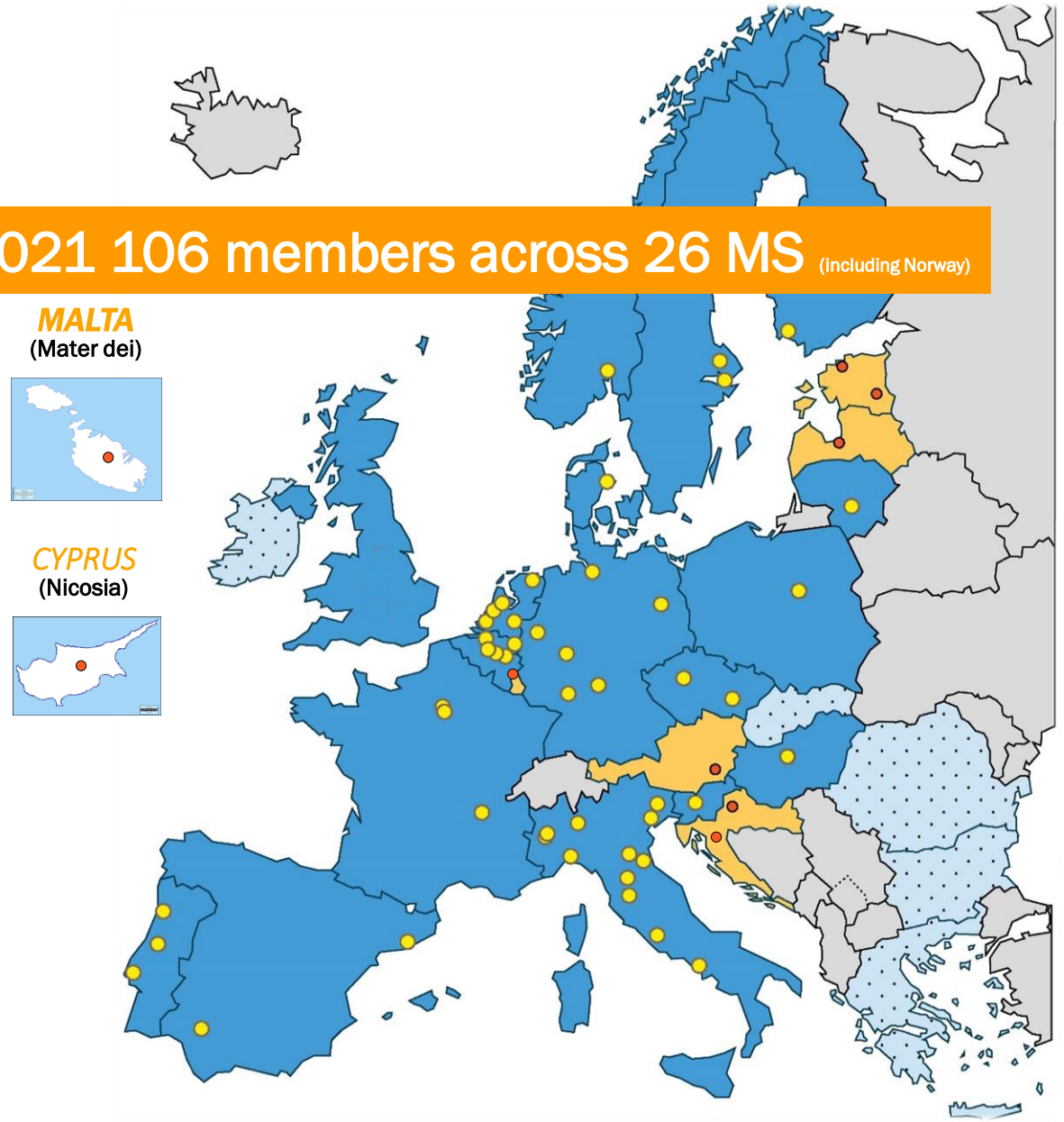
Sub-thematic areas

2017
66 full members across 17 Member states

2020
+9 APS across 7 new Member States

July 2021
+38 new members across 16 MS (3 new: (GE- RO- IE)

July 2021 106 members across 26 MS (including Norway)



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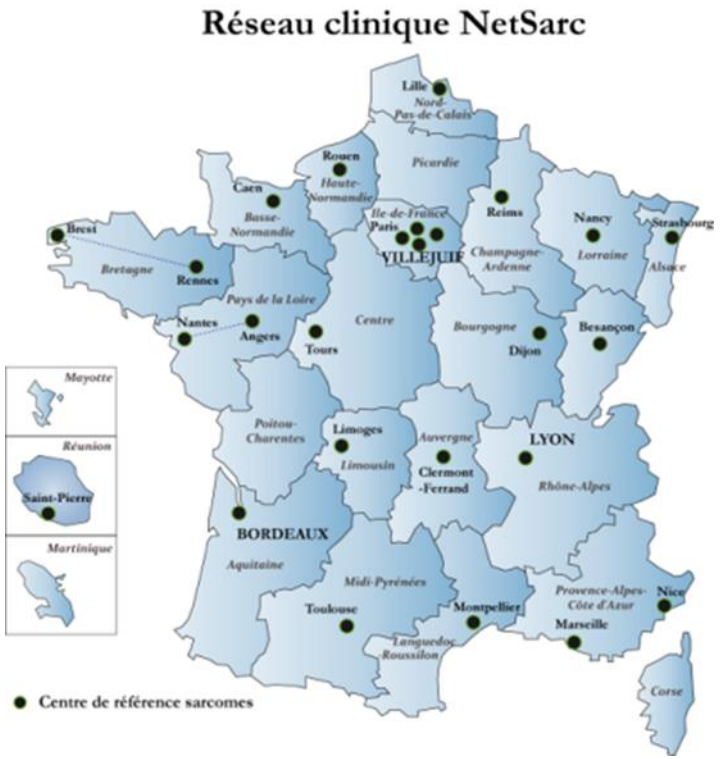
EURACAN OBJECTIVES AT 5 YEARS : ALL INVOLVING SHARED DATA AND REGISTRIES

- **Increase** access to pathological diagnosis and associated treatments across all EU Member States
- **develop** medical training programmes to increase and harmonise the quality of cares,
- **involve patient advocacy groups** and assist them in the wide dissemination of educational tools,
- **implement "roadmaps"** for referral and self-referral of patient to expert centers,
- **develop and continuously** review Clinical Practice Guidelines (CPGs),
- initiate and **promote** novel translational research programs (and associated tools – e.g. set of multinational databases and tumour banks),
- **interact** with key national international actors/networks involved in cancer care and research and beyond, with other rare diseases stakeholders.

Shared data & Cancer registries

- To improve
  - Diagnosis
  - Epidemiology
  - Optimal primary treatment

From a national to a EU Database



SarcomaBCB

La Base clinico biologique nationale Sarcomes (BCB Sarcomes)

Recommandations sarcomes période COVID-19 – LIEN
Sarcoma guidelines COVID-19 – LIEN

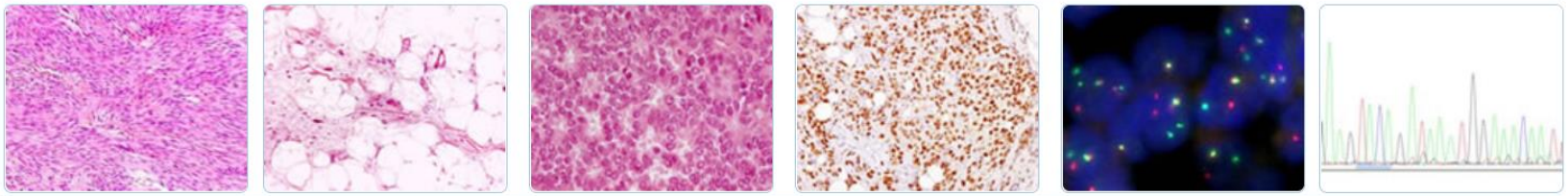
La Base clinico biologique nationale Sarcomes (BCB Sarcomes)

Les sarcomes sont des tumeurs rares et hétérogènes (5000 nouveaux cas / an en France, avec 80 types différents), complexes à traiter. L'amélioration des connaissances et de la prise en charge des patients nécessitent la mise en commun des données et matériels biologiques au sein d'une base de données nationale.

Depuis 2011, 14 bases de données clinico-biologiques (BCB) ont été créées avec le soutien de l'INCa (lien). La base nationale sarcome, appelée BCB Sarcomes, rassemble actuellement les données d'environ 108 000 patients atteints d'un sarcome ou d'une tumeur conjonctive à malignité intermédiaire. Ces données proviennent des centres experts sarcomes.

La BCB Sarcomes contient des informations anatomopathologiques, cliniques, moléculaires, thérapeutiques et évolutives, ainsi que les données sur les échantillons disponibles et les pratiques médicales. Cette base de données nationale est indispensable et constitue un outil majeur pour progresser dans la prise en charge des patients et améliorer leurs traitements.

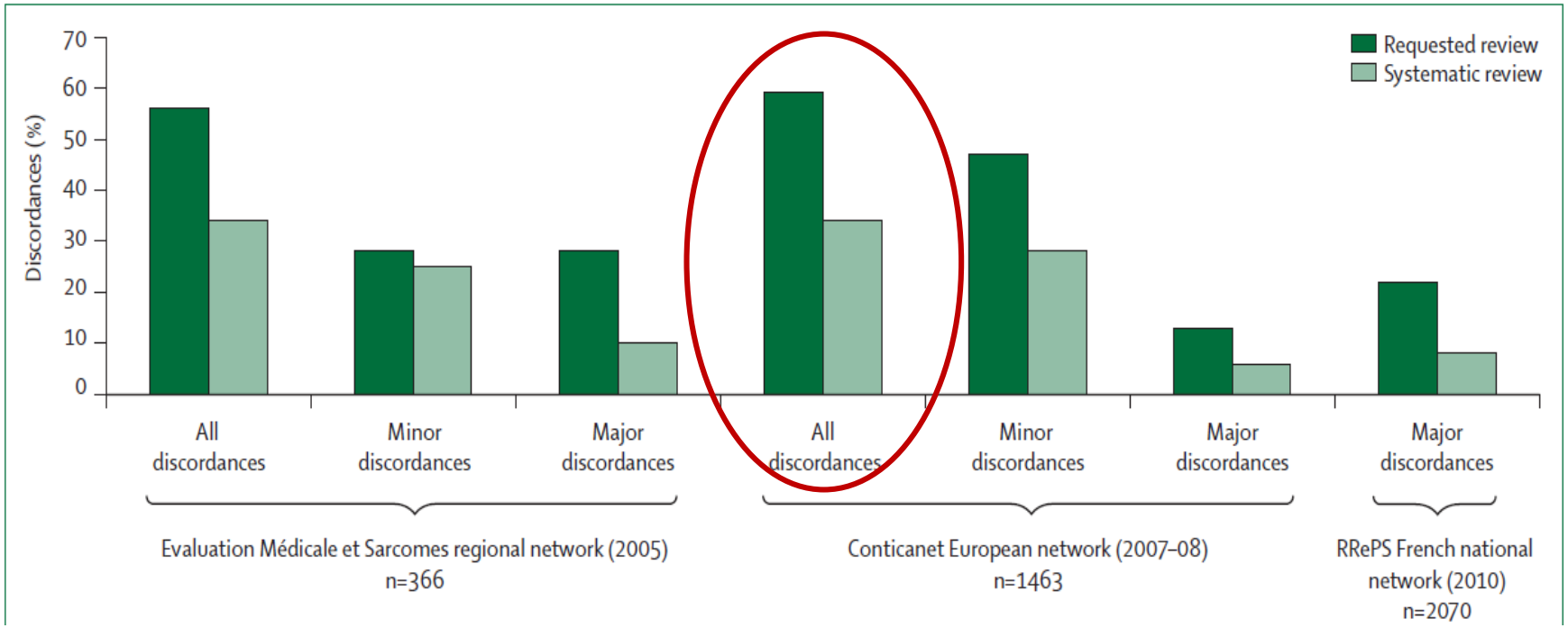
Des informations plus détaillées sur la BCB Sarcomes sont disponibles sur le site expertisesarcome.org .



Contenu de la base de données

- Patients : 108170
- Métastases : 6681
- Lignées cellulaires : 25
- Immuno-Histochimie : 22674
- RCP : 164301
- Tumeur primaires : 108789
- Lignes de chimiothérapie : 12735
- Paraffines : 32250
- Biologie moléculaire : 10163
- Inclusions essai clinique : 4747
- Récidives locales : 5409
- Prélèvements : 94762
- Tissus congelés : 13058
- Echantillons de sang : 1120

FP6, FP7, H2020 projects



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

Perrier, et al 1014, 2018, 2020

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

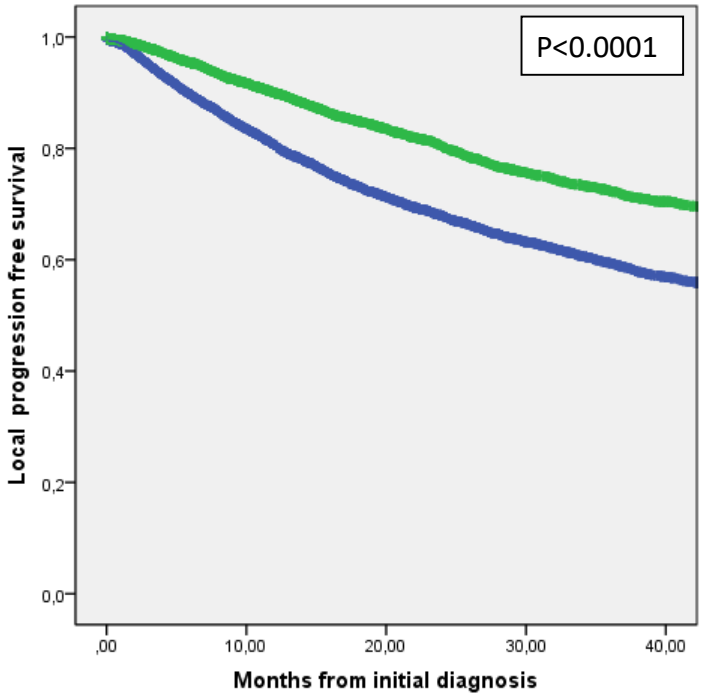
Ordered incidences of sarcomas and connective tissue tumors in NETSARC & published clinical trials

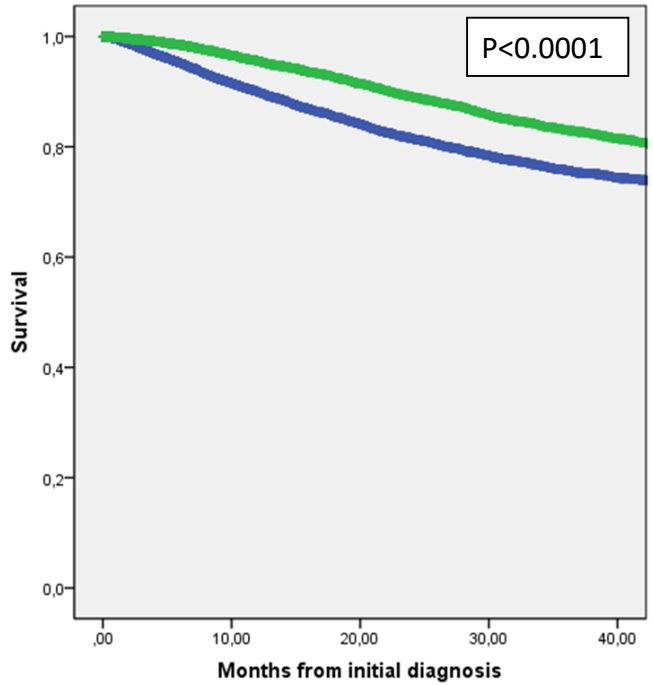
Histotypes	Total	Incidence	Ph III	RPh II	Ph II
	(2013-2016)	/10e6/year			
	25172	**95,104**			
Incidence >10/10e6/year					
Fibroblastic and myofibroblastic tumours	5274	19,977			
Gastrointestinal stromal tumors (GIST).	3272	12,394			
Adipocytic tumours	3247	12,299			
ALL Undifferentiated sarcoma	2717	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	Incidence	Ph III	RPh II	Ph II
	(2013-2016)	/10e6/year			
		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	Incidence	Ph III	RPh II	Ph II
	(2013-2016)	/10e6/year			
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 mesenchyr	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			

Survival of sarcoma patients operated in reference centers (green)





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

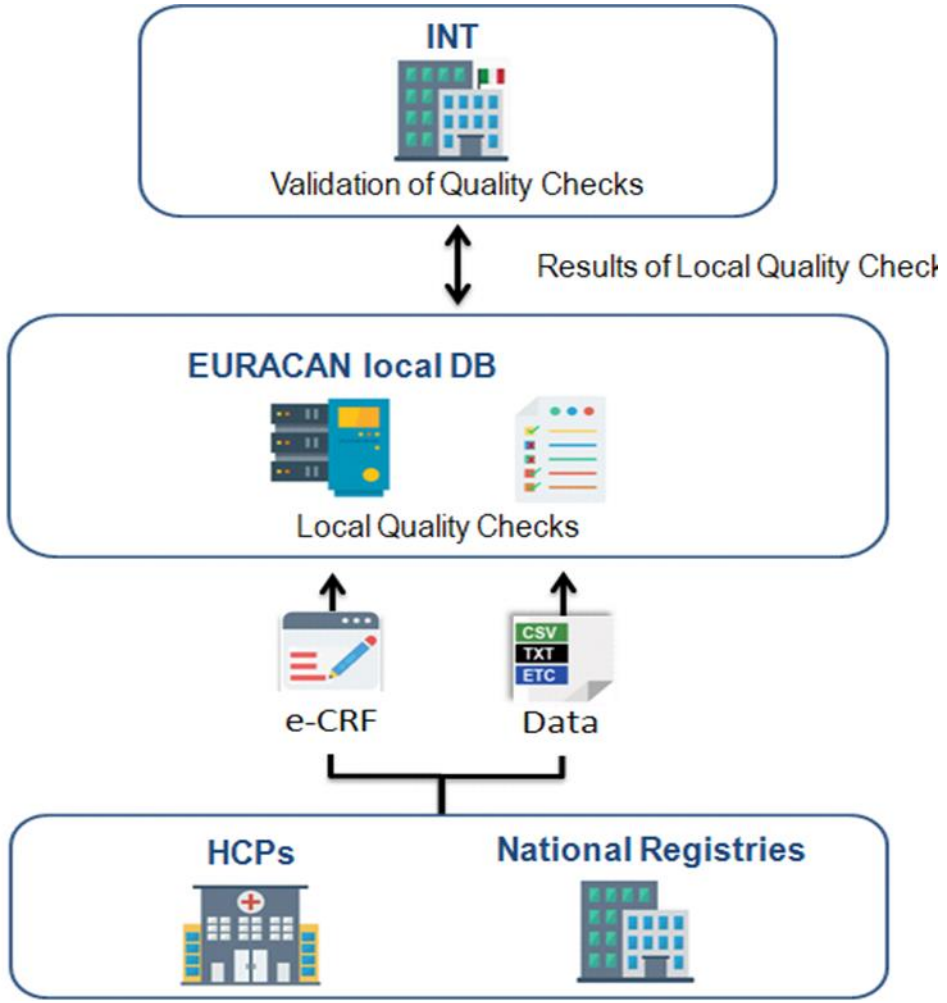
Shared data & Cancer registries

- To improve
  - Academic clinical and translational research

STARTER
STarting an Adult Rare Tumour European Registry

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

- 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



TRacKING

European observatory of NTRK fusions and other actionable fusions

EURACAN

European network for Rare adult solid Cancer

Shared data & Cancer registries

- Communication
  - Connecting patients and doctors
  - International MDT : quick, easy, cheaper, simpler

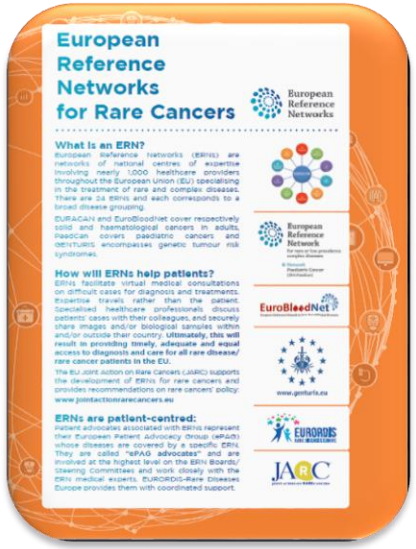
COMMUNICATION & DISSEMINATION : EURACAN.EU

New EURACAN website

website Newsletter

ECP

ECP Newsletter



Conclusions

- Oncology is changing rapidly

- Shared data and registries are needed
  - For rare and frequent cancers
- ERNs are unique tools for the EU and all member states
- Shared data and registries must be funded

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES
Share. Care. Cure.

EURACAN
European network for
Rare adult solid Cancer

Thank you for the invitation

Thank you for your attention