

Hospital management and ERNs

Prof. JY Blay

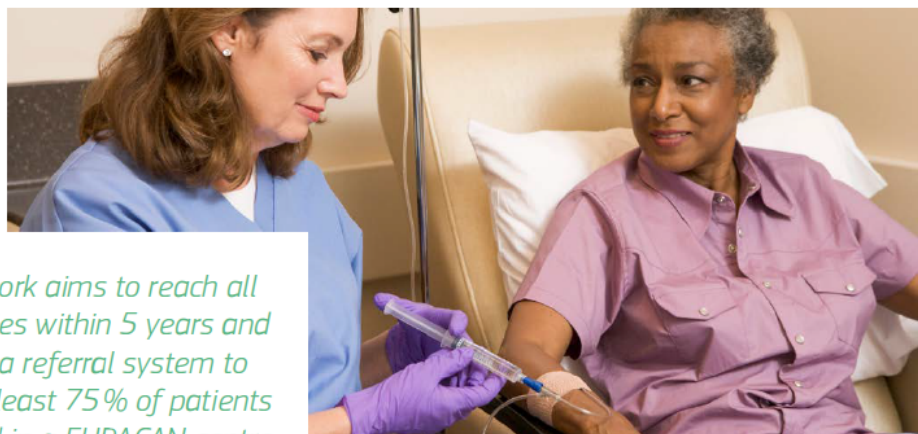
Centre Leon Berard, Lyon

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ERN on adult cancers (solid tumours) (ERN EURACAN)



More than **300 rare cancers** have been identified. ERN EURACAN covers all rare adult solid tumour cancers, grouping them into 10 domains corresponding to the RARECARE classification and ICD10. The management of rare cancers poses significant diagnostic challenges, sometimes with major consequences for patients' quality of life and outcome. Inappropriate management of these patients may also result in an increased risk of relapse, and risk of death.



The network aims to reach all EU countries within 5 years and develop a referral system to ensure at least 75% of patients are treated in a EURACAN centre.

ERN EURACAN is sharing best practice tools and establishing reference centres for rare cancers. It is also establishing regularly updated diagnostic and therapeutic clinical practice guidelines. The network aims to reach all EU countries within 5 years and develop a referral system to ensure at least 75% of patients are treated in a EURACAN centre. It seeks to improve patient survival, produce communication tools in all languages for patients and physicians, and develop multinational databases and tumour banks.

The ERN builds on pre-existing clinical and research networks that have successfully conducted clinical trials through the European Organisation for Research and Treatment of Cancer (EORTC), and established guidelines through EORTC and the European Society for Medical Oncology (ESMO). It also benefits from the work of networks formed by the European Neuroendocrine Tumour Society (ENETS) and Connective Tissues Cancer Network (Conticanet), as well as several EU research projects.

NETWORK COORDINATOR

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European Reference Network

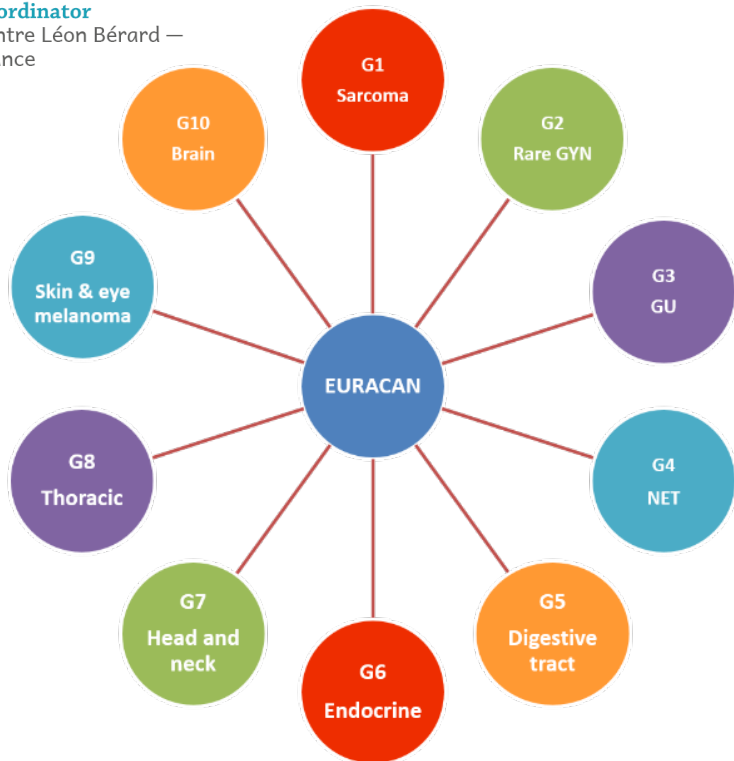
for rare or low prevalence complex diseases

Network

Adult Cancers
(ERN EURACAN)

Coordinator

Centre Léon Bérard —
France



10 domains

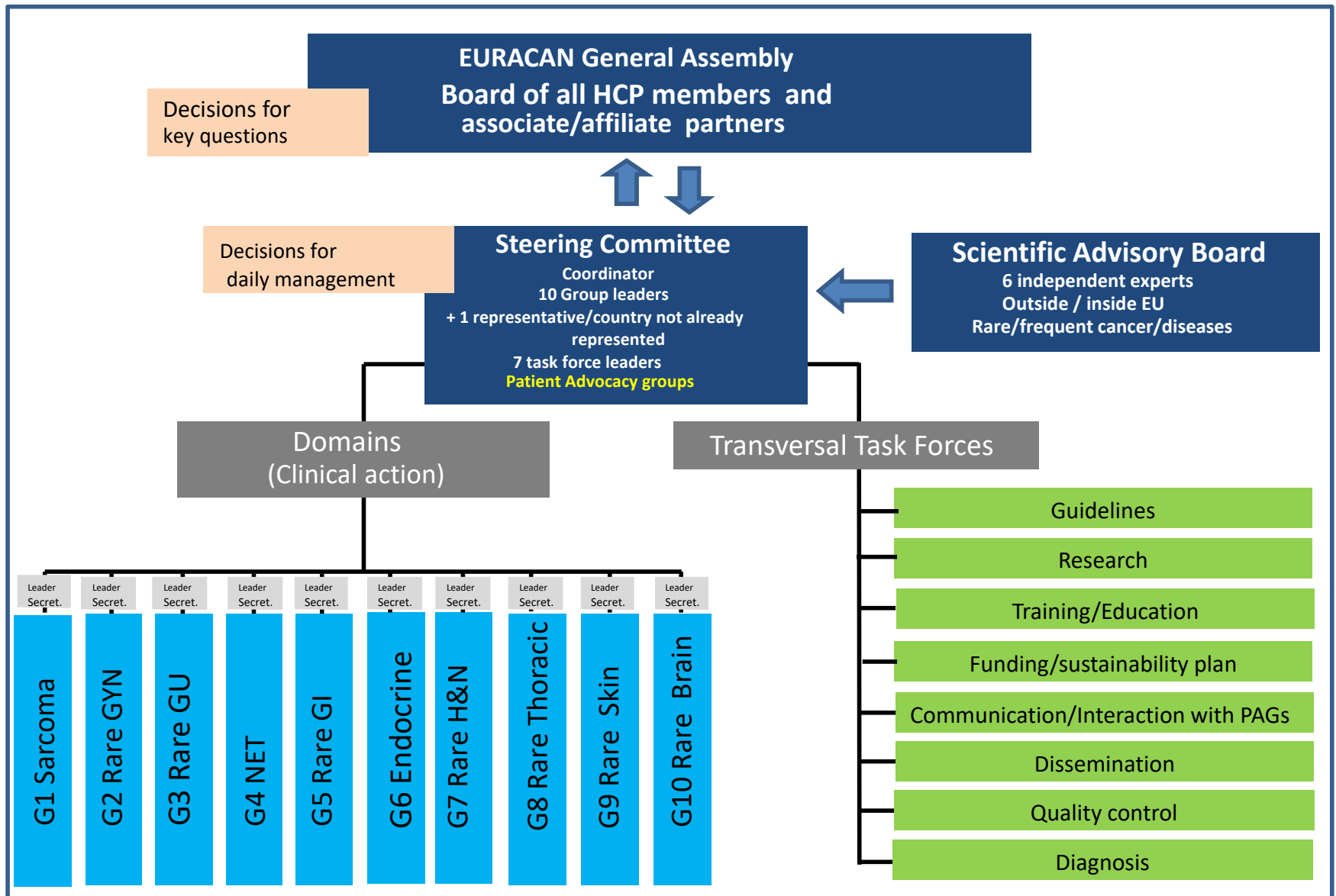
ERN EURACAN



17 European countries

RARE ADULT SOLID CANCERS

GOVERNANCE



OBJECTIVES at 5 years

- **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.

Topics

- Key roles of hospital organisation and management in the ERN operations
- To draw up common tools
- To share the best practices
- To highlight the role of national authorities

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Key roles of the hospital

- Integrate the ERN in the medical project
 - ✓ A EU reference center
 - ✓ Second opinions, international MDT
- Connect with the national initiatives
 - ✓ French NCI (INCA)
 - ✓ Share the tools develop with national support
- Support team
 - Project leader for the ERN, FTE
 - Experienced manager for EU project
 - ERN lead 0.2 FTE, + 0.8 FTE (doctors, MDT, PAs..)

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Common tools

PATIENTS' LEAFLETS

Endocrine tumours

Development of leaflets dedicated to patients and families on four subdomains:

Adrenocortical Cancer (ACC); Malignant Paragangliomas and Pheochromocytomas; Medullary Thyroid Cancer (MTC) Iodine-Refractory Thyroid Cancer; Iodine-Refractory Thyroid Cancer

COMMUNICATION/DISSEMINATION

EURACAN information leaflets have been designed along with joint leaflets on the 4 ERNs on cancers to be widely disseminated at major international congresses, meetings, patient events.

Development of a EURACAN website and management of social medias

CLINICAL PATIENT MANAGEMENT PLATFORM

The CPMS operational helpdesk joined the coordination team in Lyon to support the “customisation” of the system and make it best fit with the 10 domains’ needs and make it therefore truly operational.

The first common dataset has been developed and will now be tested during the pilot phase. The G4 domain is currently planning to hold its first online tumor board considering patient cases from the Czech Republic



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 members of EURACAN, can ask for their patient case to be reviewed. To do so an ERN coordinators convene 'virtual' advisory boards of medical specialists across different disciplines, using a dedicated IT platform (CPMS) and telemedicine tools.



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Allocate time

CLINICAL PRACTICE GUIDELINES (CPGS)

Sarcomas

ESMO-EURACAN Clinical Practice guidelines on “Gastrointestinal stromal tumours and “Soft tissue and visceral sarcomas “and **ESMO-EURACAN-PaedCan Clinical Practice Guidelines** for diagnosis, treatment and follow-up on “Bone sarcomas finalized and published by Annals of Oncology

NET

Upcoming adoption of treatment guidelines, with high level EU political support, for the tumor types within the family of NETs by building on the efforts of the European Neuroendocrine Tumor Society (ENETS).

Digestive tract

ESMO guidelines are available for **anal canal cancers** and **Biliary cancers**. The peritoneal malignancies CPGs are underdevelopment and are planned to be released in 2019.

Brain tumours

A collaboration has been established with EANO to develop a guideline on the management of **Medulloblastoma** that requires an intensive treatment.

Male Genital Organ/urinary tract

In progress is the process of summarizing and synchronizing existing clinical guidelines of treatment of testicular cancer: EAU guideline (2016); ESMO guideline (2013); Consensus Conference Testicular Cancer 2016 (Honecker et al Ann Oncol, 2018).

Clinical practice guidelines in soft tissue sarcoma, GIST and bone sarcomas. A consensus from ESMO, EURACAN and PAEDCAN.

Background

The development and implementation of clinical practice guidelines in order to harmonize practice across EU countries is one of the main goals for European Reference Networks. In 2018, the first edition of the “Gastrointestinal stromal tumours: ESMO-EURACAN Clinical Practice Guidelines for diagnosis, treatment and follow-up”, “Soft tissue and visceral sarcomas: ESMO-EURACAN Clinical Practice Guidelines for diagnosis, treatment and follow-up” and “Bone sarcomas: ESMO-PaedCan-EURACAN Clinical Practice Guidelines for diagnosis, treatment and follow-up” has been published by Annals of Oncology.

Methods

The 2018 ESMO Clinical Practice Guidelines on soft tissue sarcomas and gastrointestinal stromal tumours have been produced by ESMO in partnership with EURACAN (European Reference Network for Rare Adult Solid Cancers). A consensus among sarcoma experts was agreed during a meeting held in Frankfurt, in April 2017, joined by the members of the ESMO Sarcoma Faculty and representatives of all institutions belonging to the Sarcoma domain of EURACAN. For the ESMO Clinical Practice Guidelines on bone sarcomas, a partnership with PaedCan has been established, given the median age of some bone sarcomas.



Results

ESMO Clinical Practice Guidelines are conceived to provide the standard approach to diagnosis, treatment and survivorship. Recommended interventions are intended to correspond to the ‘standard’ approaches, according to current consensus among the European multidisciplinary sarcoma community of experts. In the 2018 version, new algorithms are provided regarding diagnosis, staging and general therapeutic strategies for the three sarcoma families.

Share experience/education

TRAINING/EDUCATION

Sarcomas

“**2nd ESO-ESMO-RCE Clinical Update on Rare Adult Solid Cancers**”. Milan, 2-4 December 2017 (partnership among ESO, ESMO, RCE, EURACAN). The “**3rd ESO-ESMO-RCE Clinical Update on Rare Adult Solid Cancers**” is due in December 2018.

“**Post-Graduate Course – Clinical Oncology: sarcomas**”. Milan, 22-26 January 2018 (partnership among the University of Milan, ESO, EURACAN). A second post-graduate course on sarcomas is due in February 2019.

-**2018 ESMO Soft Tissue Sarcoma and GIST**. Milan, 4-7 February 2018 (partnership of ESMO, EURACAN, RCE).

Gynae tumours

ESGO State of the Art conference, 4-6 October 2018.

NET

The ENETS CME program will be leveraged in future by inclusion of ERN specific trainings

H&N cancers

“**Post-Graduate Course – Clinical Oncology: head and neck cancers**”. Milan, 2-9 February 2018 (partnership among the University of Milan, ESO, EURACAN)

Thoracic tumours

Educational event on rare thoracic malignancies broadcasted live on the internet September 19, 2018

Allocate time for research

RESEARCH

Sarcomas

Collaborative TRANSCAN application titled "*Patient-derived xenograft and organoids for testing anticancer drugs and identifying novel actionable targets in rare soft tissue sarcomas*" was submitted and approved at the first evaluation step.

Digestive tract

The domain has actively participated in the world-wide research initiative on anal cancer (IIRC). The pilot study in postoperative management of biliary cancer was initiated and enrollement started;

EORTC protocol 1553

(NCT02834884)

SPECTA: Screening Cancer Patients for Efficient Clinical Trial Access

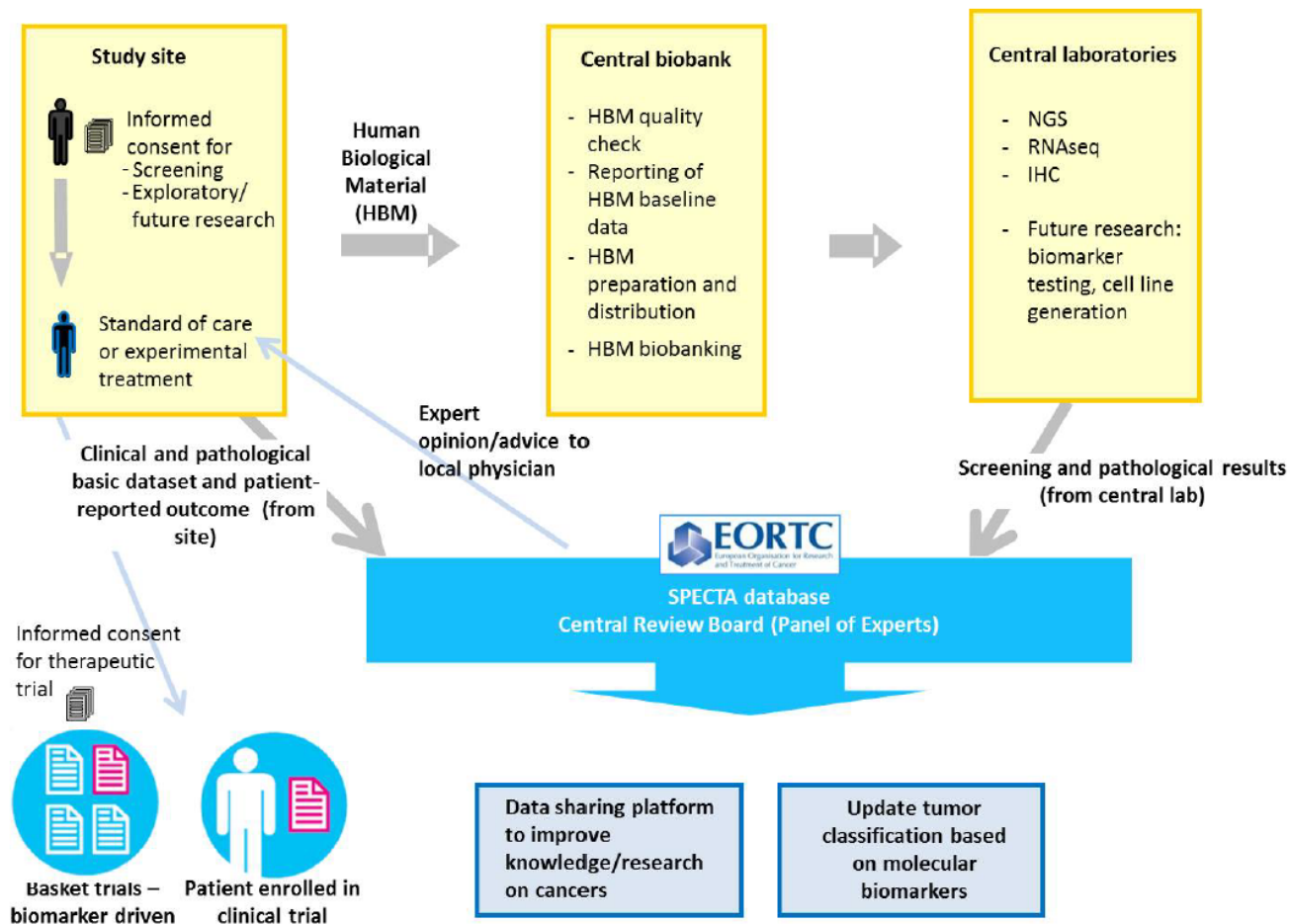


Figure 1: Description of the processes

Communication & Dissemination



How can HCP non-members of an ERN be aware of this European initiative?

In order to raise awareness on the ERNs, the Commission has carried out communication actions in particular through dedicated webpages on Europa portal https://ec.europa.eu/health/ern_en

🌟 **Press release**, for instance in occasion of the Rare diseases Day 2018, see example: <https://www.theparliamentmagazine.eu/articles/opinion/rare-disease-research-european-reference-networks-are-good-start>

🌟 **specific communication materials** both available in all EU languages

- [Brochure](#)
- [flyers](#)
- [Videos](#)

This information has been uploaded on the ECP

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Communication & Dissemination



The Commission is also supporting Member States in their effort to make information available to HCPs and patients at national level, in particular in the framework of the ongoing work on **defining referral procedures and pathways for patients** which will help them and health professionals to better get informed about the existence of the ERNs and how to access their services.

HCPs non members

Referral procedures

HCPs members



The example of the rare cancer network

- netsarc.org



NetSarc-ResOs
Réseaux de référence Cliniques
Sarcomes - GIST - Desmoïdes - Tumeurs osseuses rares



L'ANSM suspend les essais masitinib promus par AB Science. Le GSF-GETO recommande imatinib ou sunitinib en remplacement.

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Welcome to NetSarc-ResOs

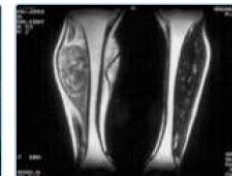
NetSarc is the French clinical reference network for soft tissue and visceral sarcomas, implemented in 2010 and approved by the INCa in 2014 (28 centers). NetSarc's RCP list.

ResOs is the French reference network for bone sarcoma and rare bone tumours, implemented in 2013 (14 centers). ResOs's RCP list.

This site gathers clinical data from patients discussed on sarcoma multidisciplinary committees (RCP) in NetSarc-ResOs centres.

These 2 networks work jointly with the French sarcoma pathological reference network (RRePS) which insures a second expert pathological review of every suspected cases.

The very structure of these networks and the automatic study of each case of sarcoma in specialized RCP improve and homogenize the management of patients with sarcomas in France, especially by making access to clinical protocols and to innovative therapeutics for all patients easier.

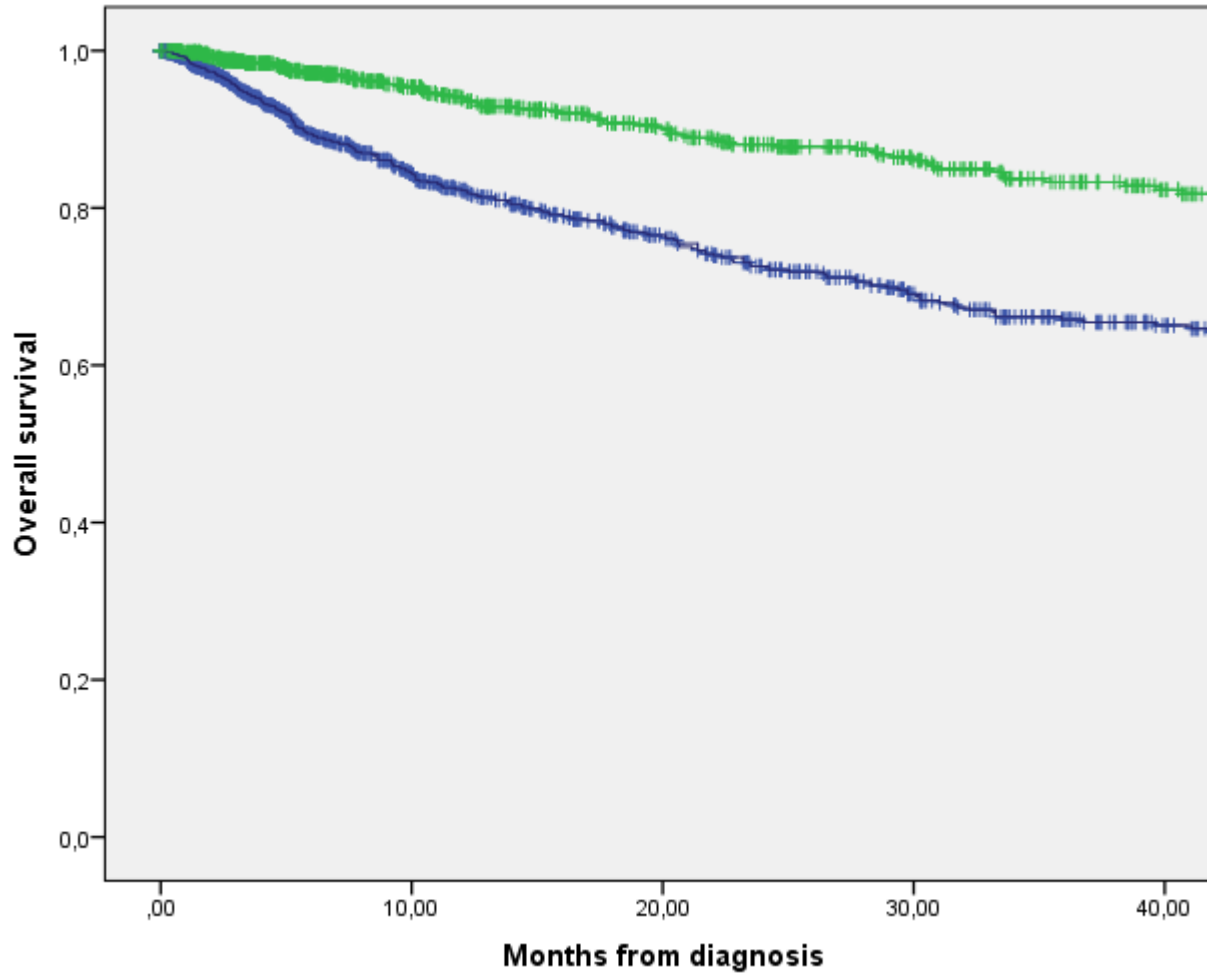


Content overview

- Patients : 49477
- Primary tumours : 49737
- RCPs : 116384
- Trial inclusions : 3225

Last change on 27/09/2018 17:17:00 by pervieux.

Retroperitoneal sarcomas



Referral procedures



How to bring rare cases to the reference HCP at country level?

- Member States have the responsibility of defining patient pathways and referral procedures

Who decides which patient will be enrolled in CPMS?

- An appropriate referral procedure could incorporate some criteria or guidelines that can be followed. Of course there is the expert judgement of the coordinating clinician in the HCP, possibly the 'panel lead'.
- It is possible to use the CPMS to have conferences between health professionals, before a patient is enrolled. They may want to use this option before effectively enrolling the patient.

A transversal team in the hospital

- The ERN representative
- The Project leader
- The administrative manager
- Doctors and researchers
- MDT
- Administrative teams