

Periodic Report 1.1– Y1 / M6-M12

EURACAN

EUROPEAN REFERENCE NETWORK ON RARE ADULT CANCERS

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| <ul style="list-style-type: none"> ▪ Call: Health programme ▪ Specific Grant agreement: 769029 ▪ Coordinator: CLB | <ul style="list-style-type: none"> ▪ Start date: 1st March 2017 ▪ Duration: 12 months |
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Report identification

Deliverable 3.4 Institution:	<i>Referencing EURACAN databases, resources, registries</i>
Period 1.1:	01/09/2017- 28/02/2018

1. Available databases registries and biobanks on all EURACAN covered tumours

G1 domain on Sarcomas

Institution	Country	DB availability	what they provide	Localized/advanced/both	Comments
Centre Léon Bérard	France	Yes	STS/BS/both	Both	National database all 26 reference centers put patients in the base (about 4000 patients per years database with now over 43000 patients since 2010)
Royal Marsden Hospital	UK	Yes	Both	Both	All clinical events in the database from diagnosis to last follow-up/ death
University Hospital of Essen	Germany	Yes	Both	Both	GIST DB and non-GIST DB. GIST DB is very comprehensive of clinical data and including genotypes. Sarcoma database is basic (characteristics and survival) and comprehensive only for LMS, UPS, SS, LPS and some rare subtypes.
University of Mannheim	Germany	Yes	Both	Both	
University Hospital of Motol	CZR	No	Both	NA	
Aarhus University Hospital	Denmark	Yes	NA	Both	Not only institutional but considered population-based since it includes all sarcoma cases diagnosed and treated in West Denmark. GIST in a separate DB.
Erasmus MC	Netherlands	No	Both	NA	Only LPS database, from 1980; fields attached.

Oslo University Hospital	Norway	Yes	NA	Both	
Istituto Nazionale Tumori	Italy	Yes	Both	Surgical patients	
University Hospitals Leuven	Belgium	Yes	STS	Both	
AOU Careggi	Italy	No	Both	NA	
Masaryk Memorial Cancer	CZR	Yes	NA	Both	Validated epidemiology data about all type of tumor from Czech National Oncologic Register (NOR) since 1977, which is being managed by the Institute of Health Information and Statistics (UZIS CR). See in English: http://www.svod.cz/?sec=oprojektu .
Istituto Regina Elena	Italy	No	HG osteogenic sarcoma Ewing sarcoma	NA	In the process of establishing a common DB for all EURACAN domain
Virgen del Rocío University Hospital	Spain	Yes	NA	Both	Still under construction. No data on items collected.
Citta della Salute	Italy	Yes	Both	Surgical patients	Only musculoskeletal, visceral sarcoma only partially and since 2012

Institute of Oncology Ljubljana	Slovenia	Yes	Both	Surgical patients	Patient's characteristics, clinical presentation of the disease, preoperative radiologic findings, preoperative MDT decision, pathology, stage of the disease, postoperative complications, Clavien-Dindo classification, hospital stay, follow up (date of local, regional or systemic relapse), treatment of relapses, date of last follow up.
University Medical Centre Groningen	Netherlands	Yes	Both	Surgical patients	

G2 domain on rare gynecologic tumours

Institution	Country	DB availability	what they provide	Localized/advanced/both	Comments
Imperial College London,	United Kingdom	All centres report an established infrastructure for cancer registries and biobanks in gynae cancers			
Leuven University Hospital –	Netherlands				
Antoni van Leeuwenhoek/Dutch Cancer Institute	Netherlands				
Turku	Finland				

G8 domain on rare thoracic tumours

Pre-identified topics	What infrastructure(s) exist	Actors concerned (clinician, researcher...)	what they provide	website	coverage	Advantages of these infrastructures
Registries	RYTHMIC AND MESOCLIN in France and THYME in ITALY	clinicians	prospective databases with follow up	www.rythmic.org and www.mesoclin.org	France and Italy	for rythmic and mesoclin, systematic enrollment of all patients
Biobanks	RYTHMIC and MESOPATH in France		FFPE specimens from french patients with thymic tumors and mesothelioma		all cases	for rythmic and mesoclin, systematic enrollment of all patients

1. Next period objectives

The referencing of available database and registries for all pathologies will be carried out on the next year.