

- Epidemiology and treatment patterns in Soft Tissue Sarcoma (STS): a retrospective analysis on French expert centers databases

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Last update : 06/21/2016 | Version : 1 | ID : 73335

General

Identification

Detailed name Epidemiology and treatment patterns in Soft Tissue Sarcoma (STS): a retrospective analysis on French expert centers databases

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL: 910390

General Aspects

Medical area Cancer research

Pathology (details) Soft Tissue Sarcoma (STS)

Health determinants Healthcare system and access to health care services

Keywords Soft Tissue Sarcoma (STS)

Scientific investigator(s) (Contact)

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Collaborations

Participation in projects, networks and consortia Yes

Details Partenariat public-privé : French Sarcoma Group (GFS) - MERCK

Funding

Funding status Private

Details Merck

Governance of the database

Sponsor(s) or organisation(s) responsible French Sarcoma Group (GFS)

Organisation status Public

Presence of scientific or steering committees Yes

Labelling and database evaluation Scientific committee

Additional contact

Main features

Type of database

Type of database	Study databases
Database recruitment is carried out by an intermediary	A selection of health institutions and services
Database recruitment is made on the basis of:	Another treatment or procedure
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Retrospective databases analysis (RRePS, NetSarc, and Conticabase) by the French Sarcoma Group (GFS)

Database objective

Main objective	<p>To describe the treatment patterns of advanced (unresectable locally advanced or metastatic) STS (including viscus sarcoma) patients in France.</p> <p>Secondary objectives:</p> <ul style="list-style-type: none">- To describe STS (including viscus sarcoma) patients characteristics (sociodemographic data, type of sarcoma, histological subtype, tumor location, stage of the disease etc).- To assess the STS (including viscus sarcoma) incidence in France- To describe STS diagnosis (anatomopathology double review) and treatment history- To describe the duration of the different treatments of STS disease
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Inclusion criteria	Patients with a diagnosis of STS, aged > 18 years-old, registered in the Conticabase/NetSarc/RRePS databases between January, 1st 2012 and December, 31st 2013 by a French expert center participating in the study between January, 1st 2012 and December, 31st 2013.
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Population type

Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
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Population covered	Sick population
Gender	Male Woman
Geography area	National
Detail of the geography area	France
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	01/01/2012
Date of last collection (YYYY or MM/YYYY)	31/12/2013
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	Conticabase: N = 1099 / NetSarc: N= 4551 / RRePS: N=6812
Data	
Database activity	Data collection completed
Type of data collected	Clinical data
Clinical data (detail)	Medical registration
Details of collected clinical data	Sociodemographic characteristics of patients; Sarcoma epidemiology (type of sarcoma) ; STS epidemiology (histological subtype, tumor location, tumor depth, grade, stage at diagnosis, stage); Diagnosis (anatomopathology double review by an expert center, initial diagnosis, confirmatory diagnosis; Unresectable locally advanced or metastatic STS (1st line systemic treatment, 1st line CT and drug type, diagnosis date of unresectable locally advanced/metastatic stage, initiation date of the 1st line CT, date of progression after 1st line treatment, 2nd, 3rd and 4th line CT and drug type)
Presence of a biobank	No
Procedures	

Data collection method	Extraction, treatment and analysis of the RRePS, NetSarc and Conticabase databases by the French Sarcoma Group (GFS)
Participant monitoring	No
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	1697 poster sarcome colloque pharma epi 9juin15 ok.pdf
Description	Colloque PEP, juin 2015
Link to the document	1772 poster sarcome VF.pdf
Description	ISPOR, novembre 2015
Link to the document	PEP2015_12_BCBSarcome_Coindre.pdf
Description	Communication orale, colloque PEP, juin 2015
Access	
Presence of document that lists variables and coding procedures	No
Terms of data access (charter for data provision, format of data, availability delay)	Methods of access are currently being defined Contact: juliette.longin@merckgroup.com
Access to aggregated data	Access on specific project only
Access to individual data	No access